

The Société Alzheimer Society of Ottawa-Hull
Day Away/Home Assistance
Programs Evaluation:

Final Report

Prepared for the
Ministry of Community and Social Services
by Evalusearch Research Consultants

Acknowledgement

We would like to express our thanks to the staff of the Day Away/Home Assistance Programs for their whole-hearted support of the program evaluation and their careful compilation of data. In particular we would like to thank Mrs. Fran Hadley, Program Director, who provided consistent assistance throughout the evaluation and who could retrieve information on a moment's notice.

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I. EXECUTIVE SUMMARY

The Day Away and Home Assistance Programs are two conjoint programs administered through the Société Alzheimer Society of Ottawa-Hull and funded through that Society, the Ontario Ministries of Community and Social Services, and Health. The evaluation of these programs has been conducted by Evalusearch Research Consultants under contract with the Ministry of Community and Social Services. The programs consist of a therapeutic day program and a home assistance program to Alzheimer's Disease individuals and their caregivers living in the community in the Ottawa area.

Program effectiveness has been assessed from two standpoints: program operation and program outcome.

Program operation

Analysis of operational data indicated that programs are operating as they were designed. All program components which the Programs had planned to offer to clients, caregivers, and the community were extensively provided.

Summary of Results of Operational Analysis

1. Clients and caregivers in the two programs are receiving different program components reflecting the different focuses of the two programs. Day Away provides a therapeutic day program while Home Assistance attempts to transfer case management to appropriate community-based agencies.
2. Interviews with a sample of caregivers indicated that caregivers were extremely well satisfied with the various program components.

3. All caregivers who still had clients living at home had some support either professional or from family or friends other than the service they received from the programs. Most caregivers felt these support services were adequate. Of those who felt support was not sufficient, respite care and homemaking were the services most often lacking.
4. Almost 3/4 of caregivers reported that taking care of their family member had become more difficult during the past six months. Most caregivers cited progression of the disease and/or illness in the family as the reasons for increased difficulty.
5. During personal interviews with staff, all but one staff member felt that additional program staff were required.
6. Community agencies surveyed expressed a high level of satisfaction with the programs and felt they filled an important gap in the community. Referral relationships between the programs and other agencies were considered very good.

This operational analysis has shown that the programs offer a wide variety of program components to both clients and caregivers; that the two programs emphasize different program components; that caregivers are extremely well satisfied with services received; and that the program has become an integral part of the service delivery network.

Client Outcome

Family burden was selected as the primary measure of program outcome. Given the degenerative nature of Alzheimer's Disease, the degree to which level of burden can be reduced or maintained at the same level can be seen as a positive program outcome. The relationship between level of dementia and burden was also examined. Family burden and clients' level of dementia were examined at program admission and at six months follow-up.

Summary of Results of Outcome Analysis

1. One-third of clients were no longer living in the community at six month follow-up. A large number of families required assistance with institutionalization over a six month period.
2. Family burden scores and dementia scores at intake were found to have little predictive power in terms of predicting institutional placement over a six month period.
3. Dementia significantly increased for the clients remaining in the community; all but two clients deteriorated.
4. Family burden did not significantly increase for caregivers of clients maintained in the community, despite a significant increase in clients' severity of dementia.
5. Given clients' deterioration over program involvement, positive program outcome was defined as decrease or maintenance of family burden. In 2/3 of study cases, burden was reduced or maintained. In 6 cases burden increased.
6. In 3 of the 6 cases in which burden increased, this increase in burden could be attributed to extent of increase in dementia. Upon controlling for change in dementia, there were only 3 cases in which program effect was not evident.
7. A minimum of 4 delayed institutionalizations appeared to have occurred as a result of program involvement.

From this study, we can conclude that many clients will be institutionalized over a six month period given that clients at the same range of dementia are served in the future; that virtually all clients will continue to deteriorate; and that the program will be successful in assisting the majority of families who have a relative with Alzheimer's Disease living in the community.

A survey was conducted of other Alzheimer Day Programs in Canada and the U.S.A. A comparison of the Day Away/Home Assistance Programs to surveyed programs revealed a great deal of similarity in terms of objectives and services provided.

Issues to be Considered

1. Model of Service and Staffing

An alternative model of care was recommended by several staff members. Recognizing two aspects of care, short-term assessment and longer-term maintenance, they recommended a program focused on acute, early involvement with clients and caregivers, followed by a transfer of case management to existing services and/or satellite day programs. This model would allow for more efficient use of current highly skilled staff, increased client capacity, and operation of satellite day programs over a wider geographic area.

2. Clientele

It is not evident that there is a programmatic reason to exclude dementing patients other than those with Alzheimer's Disease. It may be a more efficient use of resources to extend eligibility for this service to all dementing individuals.

3. Large centres vs. smaller centres

As fewer services are available in a smaller centre, especially diagnostic and assessment services, a program established in a smaller centre may need to provide more direct service than one located in a large centre.

II. INTRODUCTION

The Day Away and Home Assistance programs are two conjoint Programs administered through the Société Alzheimer Society of Ottawa-Hull and funded through that Society, the Ontario Ministries of Community and Social Services, and Health. The evaluation of these programs has been conducted by Evalusearch Research Consultants under contract with the Ministry of Community and Social Services. The programs consist of a day program and home assistance services to Alzheimer's Disease individuals and their caregivers in the Ottawa area.

The evaluation was divided into two phases. The purpose of Phase I was to collect all data relevant to the completion of an evaluation design. During Phase I interviews were conducted with program staff and key informants to compile a program history and program descriptions. These were presented in a separate report entitled: "The Société Alzheimer Society of Ottawa-Hull Day Away/Home Assistance Programs: History and Program Descriptions". Also during Phase I, a literature review was conducted which focussed on indices of family burden and effectiveness of community programs for clients with dementia.

This report represents Phase II of the evaluation. Data have been collected and analysed from a variety of sources to determine program effectiveness. Program effectiveness has been assessed from two standpoints: program operation and program outcome. Program operation has been evaluated by monitoring of program activities in order to validate the program descriptions and through interviews and surveys of caregivers, staff and community agencies to identify strengths and weaknesses in the model of service.

To assess program outcome the evaluation has focussed on the outcome measure of family burden. Family burden may significantly influence whether an Alzheimer's Disease individual will continue to be accommodated in the family home. Given the degenerative nature of the disease, where the programs are able to reduce perceived level of burden or maintain burden at an acceptable level, it is possible to infer that burden reduction or maintenance is related to program intervention.

Other outcome measures which have been examined are institutionalization of program clients and cost savings. Information was collected from caregivers which indicates the likelihood of institutionalization for the Alzheimer's individual had the programs not provided support. Program costs for those clients for whom institutionalization was deferred have been compared to institutional care costs for equivalent time periods.

A. Major Issues and Evaluation Questions

The major issues addressed by this evaluation are: 1) whether a model of service could be developed and implemented which provides both appropriate and sufficient support services to Alzheimer's Disease individuals and their caregivers; and 2) if this model of service can be replicated in other areas requiring similar services. The evaluation objectives for Phase II of this evaluation are as follows:

1. To identify and describe the model of service including information about program flow-through, extent and means of interface with other community and/or institutionally based agencies, programs or services.

2. To pinpoint key aspects of the model, in terms of community as well as service agency prerequisites and ongoing requirements for implementation of such a program within a community.
3. To supply program outcome information as available, including benefits to clients and caregivers, cost savings to government.
4. To delineate the relationship of the Day Away program to the Home Assistance program, including movement of clients between programs, and to examine the advantages and disadvantages of a multi-service versus a single-service model.
5. To describe the program's record-keeping systems, the client and family/caregiver assessment instruments used, and the data collection procedures, indicating areas of strength and weakness and providing recommendations for improvement.
6. To conduct a survey of selected programs in other jurisdictions which offer services similar to those of the Day Away and Home Assistance programs.

B. Method

Data collected to address evaluation questions fall into two main categories: program operation data and program outcome data. Figure 1 presents the data collected which relates to these areas. The Survey of Other Alzheimer's Programs relates indirectly to program operation as it presents operational information of other existing programs.

Program Operation

1. Validation of the Program Description

In order to validate the program description, program activity was monitored over a nine-week period, October 1 to November 30, 1985. Program validation consists of monitoring key aspects of the program to document what actually occurs during program operation. Program monitoring was conducted in two formats: activity monitoring and time monitoring.

- a. Activity monitoring: For the nine week period, staff were required to record all major activities related to service provision to clients and their caregivers. In determining a "major" activity, the relevance of the activity for the client or caregiver was considered as opposed to length of time spent completing the activity. Community contacts were also recorded.

FIGURE 1 Data Collected Re Program Operation and Program Outcome

PROGRAM OPERATION		PROGRAM OUTCOME	
1. Validation of Program Description	2. Model of Service	1. Client Outcome	2. Program Cost Comparisons
- program monitoring	- client/caregiver characteristics	- client follow-up	
	- caregivers' perceptions		
	- staff perceptions		
	- community agency survey		
SURVEY OF OTHER PROGRAMS			

Instrument: The Major Activity Monitoring Form (Appendix A) consisted of three sheets on which activities related to client care, caregiver services and the community were recorded by staff in pre-coded categories. Staff recorded their activities by entering their initials under the appropriate frequency column each time an activity was completed.

- b. Time monitoring: For a two-week period, each staff member was required to record the time spent on activities related to the day-to-day operation of the program as well as activities related to service provision. The purpose of time monitoring was to determine the proportion of time spent on direct care activities and the proportion of time spent on program operational and management activities by staff type.

Instrument: Two similar instruments were designed to monitor staff time: The Program Director Activity Monitoring Form and the Staff Activity Time Monitoring Form (Appendix A). The program director and staff used their respective forms to record time spent on their activities in 15 minute intervals. The program director's form included administration and staff supervision categories, while the staff form included a more detailed breakdown of activities directed to clients.

2. Model of Service

To provide insights into the type of client/caregiver served, their satisfaction with program service and the strengths and weaknesses of the model of service, data were assembled both internally from program sources and externally from community agencies and institutions which interface with the program.

a. Client and Caregiver Characteristics

Client and caregiver characteristics were collected during Phase I for all clients processed over the six month period January to July 1985. Record review of cases processed over the period August to November 1985 was completed to note any changes in client/caregiver characteristics and to provide a caseload overview of the two programs.

b. Caregiver Perceptions

A subsample of clients was selected who had been involved in one or both programs for three months or more and who had a caregiver who could be interviewed. Caregivers' opinions were solicited on various program components including both general program services and personalized management plans as well as operational aspects of program delivery.

1. Instrument: The Caregiver Interview Form (Appendix B) was designed for personal interviews with all selected caregivers. Background information on each client was recorded on this form from case records including Hierarchic Dementia Scale scores and Family Burden Index scores from time of program admission and six month follow-up. Items included both pre-coded questions, including Likert-style rating scales for program components and services received, and open-ended questions.

ii. Procedure: To ensure lack of bias, it is often desirable to employ interviewers who have no prior relationship either with the individuals interviewed or the program which has provided service. When conducting applied research studies, however, other considerations, particularly procedures which may affect the well-being of those receiving "treatment", must be very carefully examined.

In this study, the particular characteristics of the client population coupled with the complexity and diversity of program services, made selection of interviewers ignorant of individuals with Alzheimer's Disease and program operation unfeasible.

In order to find interviewers who had a working knowledge of program operation and problems associated with the disease, the volunteer co-ordinator for the programs was contacted. Volunteers are assigned to assist one client during the Day Away program one day per week. It was felt that hiring a volunteer was appropriate for the following reasons:

1. Volunteers are knowledgeable about Alzheimer's Disease, the Day Away program and problems involved in caring for an Alzheimer's individual.
2. Volunteers have chosen to work with the demented elderly and are therefore sensitive to problems of the client and caregiver which may be attributed to Alzheimer's Disease.
3. Volunteers are experienced in communicating with the elderly. Particular skills are required in conducting interviews with the elderly.

Two volunteers were hired who had backgrounds in nursing and gerontology as well as excellent interviewing skills. These volunteers conducted all interviews with English-speaking caregivers. One interview was conducted in French by the Home Assistance program recreologist.

c. Staff Perceptions

All program staff, the program director and the volunteer coordinator were interviewed individually by the evaluators. The purpose of these interviews was to obtain information on program operation and service delivery from the perspective of the service provider. The interview format included: rating of program components; review of job description, caseload and staffing; review of implementation strategies.

d. Extent of Community Integration

Community integration was assessed through a mail-out survey (Agency Survey Form, Appendix C). Agencies and institutions which were known to provide services to Alzheimer's Disease individuals and their caregivers were selected. Questionnaires addressed referral patterns, program satisfaction, service overlap and target group served.

Program Outcome

1. Client Follow-up

Family burden was selected as the primary measure of program outcome. The degree to which level of burden can be reduced or maintained at the same level can be seen as a positive program outcome. The relationship between level of dementia and burden was also examined. Family burden and clients' level of dementia were examined at the time of program admission and six months later.

Instruments

Dementia at intake and at follow-up was assessed using the Hierarchic Dementia Scale (Appendix D).¹ The Scale computes a single dementia score based on twenty mental functions covering amnesic, cognitive and psychomotor areas. For each of the twenty mental functions a hierarchy, or subscale, was constructed. The Scale has been shown to have high inter-rater reliability (.84). Concurrent validity is high.

¹M.G. Cole, D.P. Dastoor and D. Koszyck, "The Hierarchic Dementia Scale", J. Clin. Exper. Geront. 5 (3):219-234, 1983.

Scores on the Hierarchic Dementia Scale identify the highest level of performance for each mental function. The highest attainable score is 200. While subscales may be scored separately we have used the global dementia score based on all 20 mental functions.

The Hierarchic Dementia Scale was completed by trained Program staff.

Burden was assessed using the Family Burden Index (Appendix D).² The Index provides a measure of the level of stress experienced by the family caregiver.

The Family Burden Index consists of 22 items rated on a scale from 0 to 4 yielding a maximum burden score of 88. The Family Burden Index is reported to have good reliability (.79) and validity (.72) coefficients.

The Family Burden Index is completed by caregivers. For this study the Index was provided to caregivers for completion at home and returned to the program.

2. Program Cost Comparisons

Given the degenerative nature of Alzheimer's Disease it should be expected that many clients of a community care program, no matter how successful, will eventually require institutional placement. In order to determine with a degree of certainty if a program has prevented or delayed institutionalization a control group against which results can be compared and a sufficiently long follow-up period are required.

This study was limited to a one-group only design and a short, six month follow-up period. This follow-up period is particularly troublesome in an assessment of degree of delayed placement as waiting periods in the Ottawa-Carleton Region are now approximately 12 to 18 months.

A further problem in methodology is the encouragement provided by the programs to place clients on institutional waiting lists. Thus, new waiting list placements could not be used as an index of decision to institutionalize.

²J. Zarit and S. Zarit, "Measuring burden and support in families with Alzheimer's Disease elders", Presented at the 35th Annual Scientific Meeting of the Gerontological Society of America, 1982.

Given the limitations to this study, an assessment of the programs' capacity to delay institutional placement was seen as possible only in cases in which the individual entered the programs already on a waiting list; that is, where there had, prior to contact with the programs, been a conscious resolve to place in institutional care.

Costs of institutional placement have been reported for the four institutions most often accepting Alzheimer's individuals from Day Away/Home Assistance referrals. These costs are contrasted with direct costs of Day Away/Home Assistance community care. Indirect costs of community care were not included in this cost comparison.

Survey of Other Alzheimer's Care Programs

An extensive literature review was conducted to identify other programs for Alzheimer's Disease individuals including respite, day care and home assistance. Key contact persons throughout North America (see Appendix E) were telephoned to obtain addresses of programs not indicated in the literature. All identified programs were sent a mail-out questionnaire, Survey of Programs for Clients with Alzheimer's Disease (see Appendix E). This questionnaire asked for information on client characteristics, program history, programs and services, program administration, and future program plans.

Data Analysis

Program Operation

Data collected on staff activities related to clients, caregivers, and the community; caregivers' perceptions of services received and their impact; the extent of community integration; and staff perceptions of the operationalization of the model of service have been combined to present a comprehensive picture of program effectiveness. Advantages and disadvantages of a multi-service versus a single-service model of service have been examined.

Program Outcome

Using the Family Burden Index, burden scores for clients were calculated at two points in time, at the pre-test and post-test six months later. Change scores for each client were calculated. Positive change scores indicated increases in burden, negative scores a decrease in burden.

Any decrease in burden is strongly indicative of the programs' ability to improve the family situation. Maintenance of family burden has also been considered a positive program effect. Percentages of

families with increased burden, no change and decreased burden have been presented along with the mean change scores.

As Alzheimer's individuals tend to deteriorate with time, the effect of this disease process on the patient's condition and consequent changes in burden must be considered. That is, an increase in burden may be related to a rapid deterioration of the patient's condition and be unrelated to the program.

In order to assess the effect of the disease process, that is, biological change in the participants, the Hierarchic Dementia Scale was administered concurrently with the Family Burden Index. At both points in time a measure of dementia and burden were calculated.

For all clients with complete data, dementia change scores were used to calculate the average change in dementia over the six month follow-up period. This mean dementia change score served as a baseline against which to compare individual participants.

Where increase in burden was observed the dementia change score has been compared with the mean change in dementia. This allows a somewhat subjective assessment of the degree to which increases in burden were related to deterioration in the participant independent of any program effect.

It should be noted that in this one-group design, any conclusions about program effect must be somewhat tentative. The intensive qualitative program analysis in the process evaluation of these programs will be of great importance in understanding the relationships between program service, burden and dementia.

III. The Société Alzheimer Society of Ottawa-Hull Day Away/Home Assistance Programs: Program Descriptions

The Société Alzheimer Society of Ottawa-Hull Day Away/Home Assistance Programs are conjoint programs providing services to persons with Alzheimer's Disease residing in the community. The two programs share staffing, office space, administration and other resources. The Day Away Program provides therapeutic day care for persons with Alzheimer's Disease while the Home Assistance Program provides therapeutic services to Alzheimer's Disease individuals and their caregivers in the home.

The Day Away Program operated on a volunteer basis while funding was pursued through the Société Alzheimer Society of Ottawa-Hull. Fran Hadley, R.N., currently the program's director, developed and implemented the day program on a volunteer basis one day per week for one year. The Société Alzheimer Society of Ottawa-Hull also prepared a proposal for funding of a Home Assistance program. The Ministry of Community and Social Services approved funding of the Day Away Program to commence November 15, 1984, and the Ministry of Health provided funding of the Home Assistance Program as of March 1, 1985.

Physical Site

The program is housed at the Elisabeth Bruyère Health Centre. Extensive renovations were required to create a home environment for the Day Away Program. A large room is divided into kitchen, dining and living room areas. A cloak room and a bathroom easily seen and

accessible to clients are located on-site. In furnishing and decorating the premises, care was taken to reduce unnecessary sensory stimulation and perceptual distortion.

Staffing and Administration

The program director is a registered nurse. She coordinates both programs, spending two-thirds of her time on the Day Away Program and one-third on the Home Assistance Program. The assistant program director, also an R.N., works full-time in the Day Away program. An R.N.A. and a recreologist each work one-half time exclusively on Home Assistance. An occupational therapist, a social worker and a family support coordinator share their time between the two programs. A total of 5.7 full-time equivalent staff service these two programs. The programs are administered by a volunteer body, the Société Alzheimer Society of Ottawa-Hull.

Programs' Objectives

The objectives of the Day Away/Home Assistance Programs are:

1. To delay the institutionalization of the client with Alzheimer's Disease, while maintaining the optimum quality of life.
2. To reduce the burden to the caregiver of caring for the client with Alzheimer's Disease.
3. To maintain for as long as possible the functional level of behaviour in the client with Alzheimer's Disease.
4. To develop a standardized approach to the care of the client with Alzheimer's Disease.

5. To increase the awareness of the community and the knowledge of professionals regarding the effective management of the client with Alzheimer's Disease.

Client Assessment

The referred individual must have a diagnosis of Alzheimer's Disease confirmed by a neurologist and/or a geriatrician and be living in the community to be eligible for admission into the programs.

Clients are assessed for their suitability to the programs in their homes. The assessment consists of the administration of the Evaluation Protocol especially designed for this program, the Hierarchic Dementia Scale, and the Family Burden Index. The Evaluation Protocol collects general information: medical, occupational and family histories; and problems identified by the caregiver. A functional evaluation in terms of Activities of Daily Living and homemaking skills is also completed. The Hierarchic Dementia Scale includes measurements of cognitive, language, perceptual, motor, and memory abilities. The Family Burden Index provides a measure of level of stress the caregiver is experiencing and is left with the caregiver to complete and return at a later date. Based on the results of the neurological assessment and the home assessment components, a team conference is held to discuss the suitability of the programs for the client and a plan of action is outlined.

The Day Away Program

The first six weeks of attendance in the Day Away Program are a probationary period during which assessment of functional and social abilities continues. A second team conference is held at the end of this period to determine whether the client should remain in the program. Specific problem areas are identified and addressed in an individual client and family care plan.

Three groups of eight clients each attend the program one day per week, Tuesday, Wednesday, or Thursday from 9:00 a.m. to 4:00 p.m. A half day Monday morning program (9:00 a.m. to 1:30 p.m.) is provided for an intake group of six clients who will eventually enter one of the full day programs. Fridays are reserved for staff education, charting and program development. The client to staff ratio is 4:1. On average, three volunteers per day assist with program operation. The Day Away program is currently filled to capacity and has a waiting list.

Daily Program

A daily program schedule is followed to maintain consistency and create a familiar routine. The day begins with an orientation period to affirm the place, date and membership of the group. A theme is chosen for discussion, in most cases revolving around the day's activities. An activity period follows which may include crafts, woodworking or activities of daily living. Activities have an end purpose, are adult oriented and designed to tap residual skills and provide a sense of achievement. Following a "coffee break" there is an exercise period and then individual programs are carried out until lunch. Clients

assist with the meal preparation. Afternoon activities include activities of daily living, gross motor activities which may include a walk, shuffleboard or bowling and a relaxation and socialization period. This basic outline of daily activities is flexible and frequently includes outings such as strawberry picking, boat cruises, picnics and barbecues.

Although much of the program is social in nature, there are many therapeutic components. Program activities are broken down into many steps, ensuring that each person is able to participate in the activity in some way and therefore contribute to group cohesiveness. Within a group setting, individual programs are carried out for each client by carefully planning program activities and social interactions which take into account the capabilities of each group member.

Most caregivers participate in maintaining a journal which records experiences with the client over the week. In turn, staff record experiences with the client in the journal the day the client attends the program. The journal allows for close contact between staff and caregivers, identification of potential problems before a crisis evolves, and feedback on management techniques for identified problems.

All Day Away clients are re-evaluated at six month intervals, including the readministration of the Hierarchic Dementia Scale and the Family Burden Index. The treatment plan is revised on the basis of this evaluation.

The Home Assistance Program

Typically, Home Assistance Program staff visit clients weekly for an average of four weeks. The first two visits focus on collecting assessment information. An interdisciplinary team conference is then held to develop a plan of action which is reviewed with the caregiver. Typically a plan of action would include the development of a program of management techniques for the home (e.g., toileting, bathing, dressing) and accessing of existing community-based services, most commonly Chronic Home Care. As well, the provision of counselling and education to the caregiver is an important component of the Home Assistance Program in preparing the caregiver for the client's care in the future. At the final home visit, the staff member may visit the home with the staff member of the referred agency in order to review the plan of action, ensure management techniques are clearly understood and that case management can be carried on by the referred agency and/or the caregiver. As soon as other staff are in place, Home Assistance is discontinued. Home Assistance is maintained only in cases in which required services cannot be accessed from other existing agencies.

Under the auspices of the Home Assistance Program are the Family Support Groups. Groups are advertised to the membership of the Société Alzheimer Society of Ottawa-Hull and the general public as well as the Program's caregivers. Meetings are held every two weeks for seven sessions beginning with an information session to determine the interests of the group. Following the seven sessions, the Family Support worker will assist in the transition to a self-help group, if desired, but will not participate within the group on a long-term basis.

One French-speaking group is being considered while three English-speaking groups are currently held with a range of 12 to 31 persons per meeting attending these groups.

IV. OPERATIONAL ANALYSIS

A formative evaluation involves the examination of all processes related to program operation as well as specific outcome measures chosen to measure program effect. Particularly in evaluations of innovative programs such as the Day Away and Home Assistance programs, it is important to analyze the operational aspects of service delivery in terms of the strengths and weaknesses of the model of service. A program is more than the sum total of its participants and its service providers. The subtle and complex interrelationships between clients, service providers and the service network as a whole are the foundation of a community program. The examination of these interrelationships is fundamental to the assessment of program effectiveness.

A. Validation of the Program Description

In order to validate the program description, i.e., to document the degree to which main activities described by the program are actually being performed, program activity was monitored over a period of nine weeks, October 1 to November 30, 1985. Program validation consists of monitoring key aspects of the program to document what actually occurs during program operation.

Program monitoring was divided into activity monitoring related to service provision and time monitoring (see Fig. 2). Each was collected at different time periods. Activity monitoring was conducted for seven weeks for each client involved in the programs and their caregivers. Over this time period, community contacts were also recorded. Only

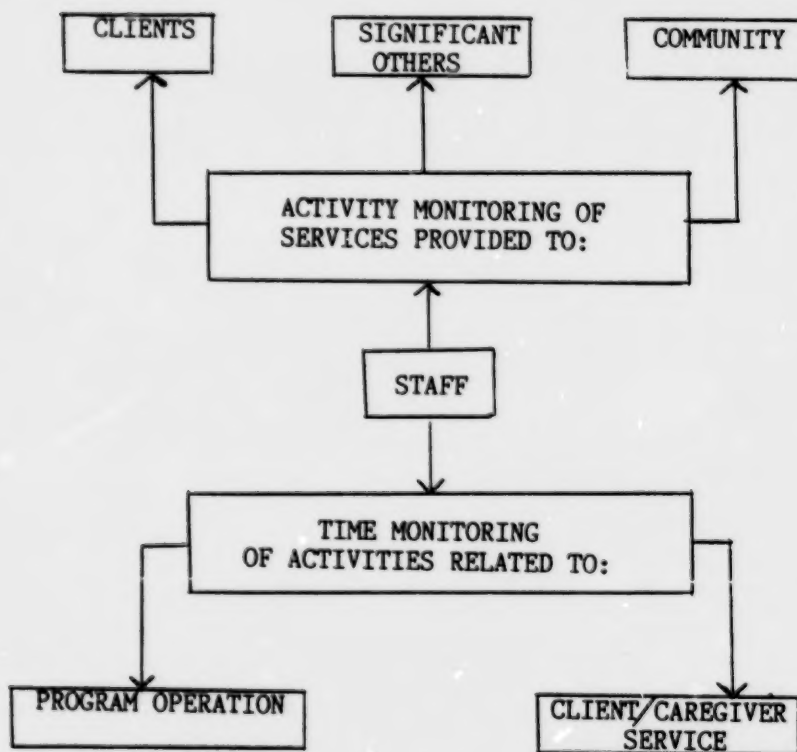


Figure 2. Program Monitoring Conducted by Staff

activities related to service provision were collected during the activity monitoring phase. Activities were recorded by staff independent of time spent on these activities. The purpose of activity monitoring was two-fold:

1. to document the extent and type of program components provided to clients, caregivers, and the community.
2. to document the extent and type of program components provided by program staff.

Time monitoring was conducted for two weeks by each staff member. Activities related to the day-to-day operation of the program were monitored as well as activities related to service provision.

1. Activity Analysis by Client

Over a seven week period program staff charted all program activities directed to clients and caregivers on the Major Activity Monitoring Form (see Appendix A). Not all activities provided to clients were recorded. Activities which related to the client's individual care plan were recorded. For example, when the Day Away program scheduled group exercise, only those clients who were individually assisted were recorded, as opposed to all participating clients. Activities were monitored for all clients currently enrolled in either Day Away or in Home Assistance. All Clients in Day Away also receive Home Assistance. Those receiving only Home Assistance, i.e., those clients not enrolled in Day Away, have been referred to as Home Assistance only clients. Clients in Day Away who by definition also receive Home Assistance have been referred to as Day Away clients. The purpose of activity monitoring for each client was to observe the number

and type of major activities that clients in each program might typically receive.

Clients monitored were at different stages in service provision. Some clients were at the beginning of program involvement and receiving assessment components, others had been involved in the program for many months, while others were in the process of being discharged. This scenario of activities directed to clients and caregivers does not represent the total amount of activity provided per client. Rather, it is a cross-section of program components delivered to clients and their caregivers over a seven week period.

In total, 58 cases were provided service over the seven week data collection period. Thirty-one (53%) had been enrolled in the Day Away program and 27 (47%) were receiving Home Assistance only. Number and type of activities provided to clients and caregivers are presented in Tables 1 and 2 respectively. The number of cases to whom these program components were provided are subdivided into Day Away clients and Home Assistance only clients.

Table 1 presents number and type of activities directed to clients over the seven weeks of data collection. In terms of assessment, 67% of clients either received an initial assessment (24%) or an ongoing assessment (43%). The initial assessment, typically conducted during the initial one or two home visits, refers to the administration of the evaluation protocol, Hierarchic Dementia Scale and Family Burden Index. Ongoing assessment refers to needs identification and assessment of new problems that arise during involvement with the programs. Clients being

Table 1. Number and Type of Activities Directed to CLIENTS

Activity	No. of cases			No. of contacts/case	
	Total (n=58) <u>n (%)</u>	D.A. (n=31)	H.A. (n=27)	Median	Range
1. Assessment					
a. initial assessment	14 (24)		14	2	1-4
b. ongoing assessment	25 (43)	13	12	2	1-7
c. 6 mo. follow-up	4 (7)	4	0	1	
2. Health care					
a. medication monitoring	9 (16)	7	2	4	1-6
b. health monitoring	29 (50)	23	6	3	1-5
c. health counselling	8 (14)	6	2	2	1-2
3. Activity programming					
a. recreational	32 (55)	27	5	5	1-10
b. ADL	34 (59)	28	6	4	1-18
c. communication	8 (14)	5	3	1	1-4
d. mobility (gross motor)	19 (33)	15	4	1	1-4
e. cognitive exercise	23 (40)	18	5	2	1-9
4. Beh. management techniques	17 (29)	12	5	1	1-9
5. Supportive counselling	24 (41)	16	8	2	1-7
6. Agency referral	19 (33)	8	11	1	1-3
7. Linkage with agencies	32 (55)	15	17	2	1-7
8. No. of home visits	32 (55)	16	16	2	1-6

assessed were typically contacted on two occasions. Ongoing assessments were distributed evenly over Day Away and Home Assistance clients. It appears that ongoing assessment (i.e. continued needs identification) is required by many clients. Ongoing assessment may allow for problem identification and resolution before a crisis evolves.

In terms of health care, 50% of clients had indicators of health, such as blood pressure and weight monitored by program staff over the seven week period. In addition, in nine cases, medications were monitored and in eight cases the client and/or caregiver were counselled regarding the client's health. Medication and health monitoring occurred on a regular basis for clients receiving these services; a median of four and three times respectively over the seven week period of data collection.

Activity programming is provided to clients in many areas as part of their individual management plans. Recreational programming provides the client and caregiver with recreational activities which are appropriate to the client's abilities. Over the seven week period, fifty-five per cent of clients received recreational programming a median of 5 times. Activity programming in the area of activities of daily living (e.g., eating, dressing, toileting) were also common, with 59% of clients receiving this service a median of 4 times. In terms of activity directed to clients, recreational and activities of daily living programming were the most frequently provided program components to the highest percentage of clients. One-third of clients received mobility (gross motor) programming and 40% participated in activities

directed to improve or maintain cognitive functioning, such as orientation and memory games.

Behaviour management techniques were provided to 29% of clients and supportive counselling was conducted with 41% of clients over the seven week period of data collections.

Program staff worked extensively with other community agencies on the client's behalf. In 55% of cases, program staff collaborated with other agencies regarding the client (linkage with agencies). This category included meeting with other professionals to share/teach techniques or strategies that have been devised for the client. It did not include referral to other agencies (which was provided to one-third of clients).

On the whole, activities were typically provided to clients on one or two occasions over the seven week period with the exception of medication and health monitoring (median of 4 and 3 respectively); recreational programming (median of 5); and ADL programming (median of 4).

Many of these activities were conducted during home visits. Fifty-five per cent of clients received a median of two home visits. Home visits were dispersed evenly between Day Away and Home Assistance clients.

Clients in Day Away appeared to receive more therapeutic services on the whole than did Home Assistance clients. Between 75% and 90% of Day Away clients received health monitoring, recreational and ADL programming and in approximately one-half of cases, program staff provided mobility (gross motor) programming, cognitive exercise,

supportive counselling and linkage with agencies. Home Assistance case activity was focused, for the most part, on activities related to assessment and agency contacts. Approximately one-half of Home Assistance clients received these services. These results were predictable, as the Home Assistance Program attempts, where possible, to transfer case management to the appropriate community-based agency, while Day Away is providing a therapeutic day program. It is apparent, however, that Home Assistance clients received individual programming, as service has been provided to some Home Assistance clients in all program component categories.

Table 2 presents the number and type of activities provided to caregivers of clients assessed or enrolled in Day Away or Home Assistance over the seven week period of data collection.

Education refers to the presentation of information to caregivers. Education was provided in four areas: health education, available community resources, legal and financial matters and management techniques. Health education refers to information provided regarding any disease (including Alzheimer's Disease) or health problem, or information provided to improve a client's health. Over the seven week period, one-third of caregivers received health information, information on available community resources was provided in approximately one-half of all cases, and information on management techniques was provided in one-quarter of cases. Legal and financial matters were discussed only in a few cases, virtually all in Home Assistance.

Table 2. Number and Type of Activities Directed to CAREGIVERS

Activity	No. of cases			No. of contacts/case	
	Total (n=58) <u>n (%)</u>	D.A. (n=31)	H.A. (n=27)	Median	Range
1. Education					
a. health	19 (33)	10	9	1	1-2
b. available community resources	28 (48)	10	18	1	1-3
c. legal and financial matters	7 (12)	1	6	1	1-2
d. management techniques	15 (26)	7	8	1	1-4
2. Counselling					
a. supportive	49 (84)	24	25	3	1-7
b. directive	41 (71)	20	21	1	1-6
3. Management programming	10 (17)	4	6	1	1-3
4. Agency referral	21 (36)	7	14	1	1-7
5. Ongoing assessment of caregiver's needs	26 (45)	11	15	1	1-3
6. Respite in home	4 (7)			3	1-3
7. Family support group	39 (67)				

Counselling was divided into supportive and directive counselling. An interaction was labelled counselling only if an actual counselling session was held as opposed to an informal contact where support was provided. Many interactions with clients and caregivers require caring and support from staff. This category, however, was reserved for actual counselling sessions. Supportive counselling refers to the use of supportive counselling techniques such as reflecting feelings of anger, fear, guilt or depression. Directive counselling refers to guiding the caregiver through a decision-making process. Included under directive counselling would be health counselling and in some cases, planning for the future. Most caregivers were involved in supportive and directive counselling (84% and 71% respectively) over the seven week period. It appears that counselling is an important aspect of the service provided by these programs.

Four program components were monitored that directly address the needs of the caregiver: referral of the caregiver to other agencies; ongoing assessment of the caregiver's needs, family support groups, and respite in the home. Over the seven week period of data collection, approximately one-third of caregivers were referred to other agencies for their own needs. Forty-five per cent of caregivers were contacted for re-assessment of their needs. Two-thirds of caregivers attended Family Support Groups which are subsumed under the Home Assistance Program. Four caregivers were provided respite in the home a median of 3 times. Respite in the home is provided to caregivers only when respite is urgently needed and arrangements cannot be made to access other professionals or family members to provide respite.

The extent of service directed to the needs of the caregiver speaks to the importance of attending to the caregiver's needs as well as the client's needs. Both client and caregiver needs must be considered in developing and implementing an individual family care plan.

In all categories of activities directed to caregivers, Home Assistance caregivers received more contact than did caregivers of clients in Day Away. Caregivers in both programs, however, were provided with the full array of program components.

Summary of Activity Analysis by Client Over the Seven Week Period of Data Collection

CLIENT

1. Forty-three per cent of clients received ongoing assessment (i.e., needs identification). Together with initial assessment, two-thirds of clients received assessment services. Assessment components appear to be important in identifying client needs both at the commencement of program involvement and periodically during service provision.
2. Fifty per cent of clients had indicators of health such as blood pressure and weight monitored by program staff. This service was provided primarily to clients attending Day Away.
3. Program components addressed to the highest percentage of clients as part of their individual care plans were activities of daily living programming (59%) and recreational programming (55%). Activity programming in these areas is particularly important given the difficulties individuals with Alzheimer's Disease have in sequencing (i.e. moving through a task in a step-by-step progression) and completing a task.
4. Program staff worked extensively with other agencies, collaborating with other agency staff in 55% of cases, and making referrals in one-third of cases.
5. On the whole, activities were provided to clients on one or two occasions over the seven week period with the exception of medication and health monitoring (median of 4 and 3 respectively); recreational programming (median of 5); and ADL programming (median of 4).

6. Fifty-five per cent of clients received a median of two home visits dispersed evenly between Day Away and Home Assistance clients.
7. Clients in Day Away appeared to receive more therapeutic services on the whole than did Home Assistance clients. Home Assistance case activity was focused on activities related to assessment and agency contacts. These results were predictable given the focus of the two programs. Day Away provides a therapeutic day program while Home Assistance attempts to transfer case management to appropriate community-based agencies.

CAREGIVER

1. Information on available community resources was provided in approximately one-half of cases; one-third of caregivers received health information; and information on management techniques was provided in one-quarter of cases.
2. Counselling was frequently provided to caregivers. Eighty-four per cent of caregivers received supportive counselling and 71% of caregivers received directive counselling.
3. The extent of service directed to the needs of the caregiver speaks to the importance of attending to the caregiver's needs as well as the client's needs. Approximately one-third of caregivers were referred to other agencies for their own needs, 45% of caregivers were contacted for re-assessment of their needs, and two-thirds of caregivers attended Family Support Groups.
4. In all categories of activities directed to caregivers, Home Assistance caregivers received more contact than did caregivers of clients in Day Away.

2. Activity Analysis by Staff

The purpose of analyzing activity data by staff person was to delineate the distribution of service provision activities by profession, i.e., who does what. Table 3 shows the distribution of service activities directed to clients, caregivers and the community by staff type. For each staff member, the per cent of his/her total number

of activities directed to clients, caregivers and the community has been presented.

Program Director

The program director directs her activities to all three activity areas. By far she conducted more activities related to the community (43% of activities) than did other staff. Three-quarters of her community contacts consisted of community liaison regarding the Day Away/Home Assistance Programs and Alzheimer's Disease. Thirty per cent of program director service activity was directed to clients. Almost all of these activities consisted of agency contact regarding the client. Caregiver service activity centered on counselling. In summary, the program director directed the majority of her service activities to liaison with the community and other agencies regarding the Day Away/Home Assistance programs, Alzheimer's Disease, or client information. She also frequently counselled the caregiver.

Assistant Program Director

The assistant program director, who is a registered nurse, is the only staff member who works exclusively with the Day Away Program. Her full-time status in the Day Away Program is reflected in Table 3 which shows that 93% of her service activities are directed to clients. She performed approximately one-half of health care provided to clients. As well, she was heavily involved in activity programming. Activity directed to caregivers consisted primarily of counselling.

Table 3 Distribution of Service Activities Directed to Clients, Caregivers and the Community by Staff Type

	Total n (%)	Prog. Dir. n (%)	Assist. Prog. Dir. n (%)	S.W. n (%)	Fam. Supp. Co-ord. n (%)	O.T. n (%)	R.N.A. n (%)	Rec. n (%)
A. Activities Directed to CLIENTS								
1. Assessment	102	2	14	31	23	9	19	4
2. Health care	129	7	71	4	22	4	14	7
3. Activity programming	474	1	140	91	134	40	29	39
4. Beh. man. tech.	32		10	3	7	4	6	2
5. Supportive counselling	68	3	8	18	24	7	3	5
6. Agency liaison	105	44	9	14	12	22	8	4
Subtotal	910 (58)	57 (30)	244 (93)	161 (52)	222 (53)	68 (51)	79 (51)	61 (65)
B. Activities Directed to CAREGIVERS								
1. Education	103	8	3	13	36	15	21	7
2. Counselling	244	27	12	51	102	29	13	10
3. Management programming	14			1	4	4	5	
4. Agency referral	38	8	1	13	6	2	7	1
5. Ongoing assessment	43	8	2	4	12	7	9	1
6. Respite at home	9						6	3
Subtotal	451 (29)	51 (27)	18 (7)	82 (27)	160 (39)	57 (42)	61 (39)	22 (23)
C. Activities Directed to COMMUNITY								
1. Community liaison	122	60		27	15	7	10	3
2. In-service programs	39	6		12	7	2	5	7
3. Student field placements	12	5		7				
4. Family Support Groups	40	10		18	12			1
Subtotal	213 (14)	81 (43)		64 (21)	34 (8)	9 (7)	15 (10)	11 (12)
TOTAL	1574 (100)	189 (100)	262 (100)	307 (100)	416 (100)	134 (100)	155 (100)	94 (100)

Social Worker

The social worker directed one-half of her service activity to client care. She conducted the range of services to clients, with the exception of health care and behaviour management techniques. Activities related to caregivers focused on education, counselling and agency referral. Twenty-one per cent of activities were community contacts. She was involved in all categories of community work, including liaison with the community, in-service programs, student field placements, and Family Support Groups.

Family Support Co-ordinator

Unlike the position title implies, in terms of activity, the family support co-ordinator was primarily involved in providing care to clients and caregivers, with only 8% of activities directed to the community, which included Family Support Groups. One-half of service activities were directed to client care. She was involved in providing all components of client care. Activities directed to caregivers centered on education and counselling.

Occupational Therapist

The occupational therapist also directed one-half of her service activities to client care. Within this area, she focused primarily on activity programming and agency liaison. Services to caregivers focused on the provision of education and counselling.

R.N.A.

The R.N.A. also directed 50% of his service activities to clients, providing the full range of client services, with the exception of counselling. The R.N.A. directed 39% of service activity to the caregiver, providing all program components, including respite at home.

Recreologist

The recreologist directed 65% of his activities to clients, focusing on activity programming. He provided education and counselling to the caregiver.

Conclusions

Based on an analysis of service activities performed over a seven week period, staff can be divided into three distinct role categories:

1. Community liaison

The program director conducted the majority of community liaison. She was the primary community contact person providing program information, and information regarding Alzheimer's Disease. In addition, she focused a considerable amount of activity on collaborating with agencies regarding the client.

2. Day Away client management

The assistant program director (R.N.) worked solely in the Day Away Program, directing almost all of her activity to client contact. She

provided one-half of the health care for clients. She was also heavily involved in activity programming.

3. Client/caregiver management

The remaining staff (S.W., Fam. Supp. Co-ord., O.T., R.N.A. and Rec.) provided the full range of program components to both clients and caregivers and, with the exception of the social worker, directed little activity to the community (range of 7% to 12%).

3. Time Monitoring

Staff monitored their time spent on program activities in 15 minute intervals for two weeks. The Program Director Activity Time Monitoring Form and the Staff Activity Time Monitoring Form appear as Appendix A. Activities were divided into those related to program operation, e.g., program development, charting, and travel; and activities related to the care of clients and their caregivers, e.g., client assessment, face-to-face client contact, and community liaison regarding clients.

The total number of hours per week spent on major activities was calculated for each staff person. Program director information is presented separately from other staff due to different categories of program activities.

Table 4 presents the number of hours spent over a one week period by the program director in program activities. Ninety-one per cent of the program director's time was spent on activities related to the operation of the program and 9% of her time was spent providing service to clients and caregivers. In terms of program operation, two activities required a large proportion of her time; administration of

Table 4 Distribution of Hrs. per Week Spent on Program Activities
by Program Director

	# hrs./wk. n	% of total hrs./wk.
A. Program Operation		
1. Administration	9.4	22
2. Program development	2.6	6
3. Staff development	2	5
4. Staff supervision	2.2	5
5. Community liaison-general	14.6	34
6. Student Field Placements	2	5
7. Case Conferencing	2.9	7
8. Charting	1.5	3
9. Report Writing	1.7	4
10. Travel	-	
Total hrs.	38.9	91%
B. Client/Caregiver Service		
1. Enquiries re new clients	1.3	3
2. Telephone Contacts	1.5	3
3. Face-to-Face Contact	.8	2
4. Community liaison - re clients	.4	1
5. Family Support Groups		
Total hrs.	4	9%

the program accounted for 22% of her time and community liaison-general accounted for 34% of her time. Community liaison-general refers to program-related community contacts (including in-service workshops presented and attended) and information provided to the community regarding Alzheimer's Disease. It does not include community contacts regarding Day Away and Home Assistance clients.

Table 5 presents the distribution of time spent on program activities by treatment staff. All staff are included with the exception of the program director. The assistant program director, who is a registered nurse, works full-time in the Day Away program. An R.N.A. and a recreologist each work one-half time exclusively on Home Assistance. A full-time social worker, a full-time family support coordinator, and a part-time (.7 full-time equivalent) occupational therapist share their time between the two programs.

Treatment staff allocated 44% of their time to program operation and 56% of their time to providing service to clients and caregivers. Charting and travel each accounted for 10% of total time spent. Detailed progress notes are kept on client/caregiver interactions. Travel is time-consuming due to the fact that a staff member travels on the hired bus to transport Day Away clients to and from the Program. In addition, staff make home visits to conduct initial assessments and to provide care for clients in Home Assistance.

Six per cent of treatment staff activity was spent on program development. Staff are in the process of developing an innovative program and require time to develop, test and refine strategies and therapeutic components of service.

Table 5 Distribution of Hrs. per Week Spent on Program
Activities by Treatment Staff*

	# hrs. per/wk.	% of total hrs./wk.†
A. Program Operation		
1. Program development	10.9	6
2. Staff development	7	4
3. Case conferencing	3.9	2
4. Charting	17.6	10
5. Report writing	5.2	3
6. Caseload management	5.6	3
7. Travel	17.4	10
8. Housekeeping and activity preparation	2	1
9. Community liaison-general	6	4
10. Student field placements	1.5	1
Total hrs.	77.1	44%
B. Client/Caregiver Activities		
1. Enquiries re new clients	.3	-
2. Client assessment	12.7	7
3. Face-to-face contact - DAP	36.3	21
4. Face-to-face contact - HAP	21	12
5. Community liaison re client - DAP	2.5	1
6. Community liaison re client - HAP	8.6	5
7. Telephone contacts	12.2	7
8. Family support group	3.3	2
Total hrs.	96.9	56%

* Includes all staff with the exception of the Program Director

† Any errors due to rounding.

Direct client or caregiver contact accounted for 49% of treatment staff time (i.e., client assessments + face-to-face contacts + telephone contacts + Family Support Groups). More time was spent in face-to-face contact with Day Away clients (21%) than with Home Assistance clients (12%). This was predictable as a prescribed time period is available for face-to-face contact with Day Away clients weekly whereas Home Assistance staff attempt, where possible, to transfer case management to an appropriate community-based service. More time was spent in community liaison regarding Home Assistance clients (5%) compared with community liaison for Day Away clients (1%).

All program components which the Day Away/Home Assistance Programs had planned to offer to clients, caregivers and the community were, in fact, extensively provided as confirmed by these activity and time monitoring data. Although clients in Day Away appeared to receive more therapeutic services, Home Assistance caregivers received more contact than did caregivers of clients in Day Away. These data reflect the different focuses of these two programs. Day Away provides a therapeutic day program while Home Assistance attempts to transfer case management to appropriate community-based agencies.

Based on the analysis of service activities by staff, three distinct staff role categories emerged: Community liaison was conducted primarily by the Program director. Day Away client management was primarily the responsibility of the assistant program director who is the only full-time Day Away staff member. The remaining staff provided the full range of program components to both clients and caregivers, directing little activity to the community.

Time monitoring analysis indicated that the program director's time was almost exclusively spent on program operation; whereas treatment staff devoted approximately three-fifths of their time to direct client or caregiver contact and two-fifths to program operation.

These data provide a detailed analysis of the actual operation of the programs in terms of activities directed to clients, caregivers and the community, activities performed by individual staff members and time allocation to activities. This presentation of the day-to-day operation of the program has indicated that the programs are operating as they were designed.

4. Record Review

An individual case record is maintained for each client enrolled in Day Away and Home Assistance. Case records include:

1. A face sheet
 - summarizes general information on the client
2. The Evaluation Protocol
 - collects general information, problems identified by the caregiver, medical, social, occupational, and family histories, and a functional evaluation of activities of daily living.
3. The Hierarchic Dementia Scale
 - A graph of the 20 hierarchic mental abilities subscales and total score appear on the face sheet of the form. Both initial and follow-up scores are entered on the same graph in different colours to provide a picture of change in dementia over the follow-up period.
4. The Family Burden Index
 - This form is retained in its entirety in case records.
5. Progress Notes
 - Open-ended, dated progress notes are entered for major client contacts.
6. Summary Reports
 - Results of initial assessment and conferencing are written in report form.

7. Discharge Summary

- Each professional enters comments on a discharge sheet. Date of program entry and discharge are also entered.

The evaluators retrieved client/caregiver information from case records. As a result of this process, recommendations have been made with respect to more easily accessing information and reducing charting time.

Recommendations:

1. There is no way to easily determine number of clients currently active in the programs. Each client for whom an initial assessment is conducted should receive a client identification number. These numbers should be cross-referenced for easy client identification.
2. The face sheet should be revised to include clear identification of client name; caregiver name and respective addresses. The face sheet should also clearly identify the program in which the client is currently enrolled.
3. The Protocol should be reviewed with staff to determine if any items could be deleted. This recommendation is based on the observation during case record review that information was frequently missing from the Protocol. It is also suggested that items on the Protocol be numbered and that spacing be adjusted to allow responses to be more quickly accessed. For example, the rating categories under instrumental activities of daily living should be lined up for easy scoring and reading of scores. All caregiver information should appear together, rather than being entered on two pages.
4. The Family Burden Index should not be printed on two sides, as families frequently completed only one page. Identifying items such as the client's name, date and total score should appear at the top of the form.
5. The Program should consider the appropriateness of using open-ended progress notes on a daily basis. Time monitoring indicated that treatment staff spent 10% of their time charting. Information is extremely difficult to access from these notes. Staff should review the usefulness of these notes (e.g. how often they are read in detail). Perhaps a monthly progress report plus a structured record of problems and activities would be more efficient and easier to read.

B. The Model of Service

The model of service has been examined based on information from four sources: client/caregiver characteristics; caregivers' perceptions of services received, staff perceptions of program operation; and a survey of community agencies serving Alzheimer's individuals.

These data present an in-depth picture of all aspects of program operation. Client and caregiver characteristics provide the reader with background knowledge on the type of client and caregiver to whom service has been provided. Within this context, caregiver and staff perceptions of service delivery can be evaluated. Lastly, information collected from community agencies has been analysed to determine the degree to which the programs have become part of the service network for Alzheimer's individuals.

1. Client/Caregiver Characteristics

Program type

The Day Away Program began accepting clients in January 1985 and the Home Assistance Program began in April 1985. Data have been collected on those clients for whom the Evaluation Protocol had been completed over the ten and a half month period January 1985 to 15 November 1985. A total of 84 clients with a complete Evaluation Protocol had been accepted in one or both programs during this period: 48 (57%) were in Day Away/Home Assistance and 36 (43%) in Home Assistance only. The Home Assistance program had the greatest increase in clients during the four month period August to November. The number

of clients doubled from 12 to 24. Clients eligible for the Day Away Program are given Home Assistance only at this time because of full enrollment in the day program. The longer period of program operation coupled with full enrollment in the Day Away Program accounts for the doubling of client intake for the Home Assistance Program.

Client and Caregiver Characteristics

Table 6 presents client and caregiver characteristics for clients enrolled in programs from January to November 1985. Clients had a mean age of 73.5 years with a range of 52 to 87 years. Approximately three-quarters of caregivers were spouses of clients. Spouses had a mean age of 71 years. The remaining 25% of clients were cared for by other relatives, with a much younger mean age of 50 years.

Almost two-thirds (65%) of clients were female while one half of caregivers were male. Only ten clients (13%) were unilingual French. All remaining clients either spoke English or were bilingual.

Based on caregiver reports at initial interview, 82% of clients were reported in good or very good physical condition. Fifteen clients (18%) were listed in fair or poor health. On the whole, clients were in good health with mental impairment their principal disability. Although most caregivers (71%) were also reported to be in good health, twenty-nine per cent indicated they were in fair or poor health.

Table 7 provides a description of clients' functional abilities in terms of their ability to perform various activities of daily living. This information was taken from staff's initial interviews with caregivers. In self-care skills approximately one-half of clients were

Table 6 Client and Caregiver Characteristics

<u>Client</u>		<u>Caregiver</u>	
<u>Age:</u>	<u>Mean</u>	<u>Age</u>	<u>Mean</u>
	73.5	If Spouse	71 yrs.
		If other relation	50 yrs.
(n=83)		(n=70)	
<u>Sex:</u>	<u>n</u> (<u>%</u>)	<u>Sex</u>	
male	29 (35)	male	43 (54)
female	55 (65)	female	36 (46)
(n=84)		(n=79)	
<u>Physical Condition</u>		<u>Physical Condition</u>	
	<u>n</u> (<u>%</u>)		<u>n</u> (<u>%</u>)
good/very good	67 (82)	good/very good	55 (71)
fair	11 (13)	fair	19 (24)
poor	4 (5)	poor	4 (5)
(n=82)		(n=78)	
<u>Language Spoken in Home</u>		<u>Relationship of Primary Caregiver to Client</u>	
	<u>n</u> (<u>%</u>)		<u>n</u> (<u>%</u>)
English	58 (75)	Spouse	61 (77)
French	10 (13)	Son/daughter(in-law)	15 (19)
Both	9 (12)	Sister/brother	3 (4)
(n=77)		(n=79)	

Table 7 Functional Abilities of Clients' Activities of Daily Living

<u>Self-care</u>	<u>Can do</u> <u>Unassisted</u>		<u>Can do</u> <u>With Help</u>		<u>Cannot do</u>	
	n	(%)	n	(%)	n	(%)
Bathing	30	(36)	38	(46)	15	(18)
Dressing	37	(44)	41	(49)	6	(7)
Undressing	46	(59)	27	(35)	5	(6)
Toileting	63	(75)	17	(20)	4	(5)
Grooming	45	(55)	23	(28)	14	(17)
 <u>Physical Movement</u>						
Getting in/out of bed	62	(85)	9	(12)	2	(3)
Mobility in house	75	(92)	6	(7)	1	(1)
Use of transportation	6	(8)	15	(20)	55	(72)
Use of telephone	25	(33)	12	(16)	39	(51)
 <u>Household Tasks</u>						
Grocery shopping	6	(7)	15	(19)	60	(74)
Meal preparation	4	(5)	19	(24)	58	(72)
Housework	17	(21)	18	(22)	46	(57)
Laundry	10	(13)	11	(14)	57	(73)
Money management	2	(3)	6	(8)	71	(90)

able to dress, undress and groom themselves without assistance. Three-quarters of clients were independent in toileting and approximately one-third were able to bath themselves. Most clients were either independent or could accomplish self-care tasks with some assistance.

In terms of physical movement, most clients were able to get in and out of bed and move about the house independently. Only six clients (8%) knew how to use public transportation on their own, while seventy-five per cent could not negotiate public transportation even with assistance. One-half of clients could not use the telephone.

The majority of clients were unable to manage household tasks, including grocery-shopping, meal preparation, housework and laundry, even with assistance. Ninety per cent of clients were unable to manage their financial affairs. Caregivers also reported that sixty-nine per cent of clients were subject to wandering.

An examination of clients' functional abilities demonstrated that aside from very basic self-care skills, clients were highly dependent on caregivers for virtually all their needs. Although most clients were independently mobile many were also subject to wandering.

2. Caregiver Perceptions

A subsample of clients was selected who had been involved in one or both programs for three months or more and who had a caregiver who could be interviewed. Forty-four caregivers were given personal interviews in their homes to assess caregivers' perception of the Day Away and Home Assistance Programs. Caregivers' opinions were solicited on various

program components including both general program services and individual management plans to deal with specific client/caregiver problems. Caregivers were requested to comment on operational aspects of program delivery e.g. hours of service, availability of staff, and to rate their overall degree of satisfaction with services delivered.

Lastly, caregivers were questioned about their use of other professional and non-professional services, facility placement and changes during the last six months which may have affected the care of the Alzheimer's individual. Through analysis of caregiver perceptions of program services and consideration of the changing demands on caregivers in providing adequate and appropriate care for their Alzheimer's relative, an assessment of program impact can be made.

Basic demographic information was collected on caregivers interviewed and their relatives with dementia enrolled in the programs. Comparison of client/caregiver characteristics for the subsample of interviewed cases with the total sample of cases showed differences on several variables. Table 8 shows that only nine clients (21%) were male in the subsample, while 29 (35%) were male in the total sample. Thirty-nine (89%) of these clients had participated in the Day Away compared with 48 (57%) of all clients. There were no differences between the two samples in mean age of clients or caregivers, sex of caregiver or relationship of primary caregiver to client. Thus, this subsample of cases is underrepresented in the number of male clients and over-represented by Day Away participants. On all other variables including Family Burden Index scores at intake the subsample is representative of the total client sample.

Table 8 Client and Caregiver Characteristics of Interviewed Cases (n=44)

Client			Caregiver		
<u>Age:</u>	Mean	72.5 yrs.	<u>Age:</u>	Mean	
			If spouse	70 yrs.	
			If other	50 yrs.	
			relation		
	(n=44)			(n=40)	
<u>Sex</u>	<u>n</u>	(%)	<u>Sex</u>	<u>n</u>	(%)
male	9	(21)	male	24	(55)
female	35	(79)	female	20	(45)
	(n=44)			(n=44)	
<u>Program Type</u>			<u>Relationship Primary Caregiver to Client</u>		
Day Away	39	(89)		<u>n</u>	(%)
Home Assistance	5	(11)	spouse	31	(71)
			son/daughter(in-law)	11	(25)
			brother/sister	2	(5)
	(n=44)			(n=44)	
a) Weeks in Program:	Mean	25.7 weeks			
	(n=43)				
b) Discharged from Program	<u>n</u>	(%)			
	20	(46)			
	(n=44)				

Table 8 shows that program clients of interviewed caregivers spent a mean of 26 weeks in one or both programs and 20 clients (46%) had been discharged from the programs. Of these thirteen had been institutionalized and two clients were deceased.

a. Day Away Program

Caregivers who had family members in the Day Away Program (39 clients) were asked to comment on the helpfulness of this program. Caregivers cited benefits of the program for themselves and their family members.

i. Benefits to Caregivers

The main benefit of the program reported by caregivers was the relief care for the client. Besides affording caregivers the much needed time off, the program provided peace of mind; caregivers reported that they felt confident their relative was being well-cared for. Caregivers also noted that the program gave them an opportunity to meet and share experiences with other Alzheimer's victims' relatives. Learning more about the disease process from staff and positive staff attitude did much to alleviate feelings of anxiety.

ii. Benefits to Clients

Caregivers felt that it was very beneficial to clients to have an opportunity to get out of the house. Clients appeared to enjoy the socializing aspects of the program a great deal. Caregivers reported

that the environment was stimulating and one caregiver reported that the client seemed more alert after program participation. Overall the experience for the client was reported as positive. When asked to rate the program on a scale of 1 to 5, thirty-two caregivers (83%) rated the program very helpful, i.e. gave it a score of 4 or 5.

b. Service Provision: Program Components

Interviewers provided a list to caregivers of the various services which the programs provide regularly. They were asked to identify those services which they had received and to rate their helpfulness on a five point scale ranging from not at all helpful to very helpful. Table 9 presents the percentage of client/caregivers receiving services and the degree of helpfulness for each service provided.

1. Transportation to the Day Away Program

A limousine service was hired by the program to pick up and drop off clients for the Day Away Program at their homes. As far as possible clients living in the same geographic area were assigned to the same day for program participation, to expedite travel time. Approximately one hour each way was spent in transportation of clients. Twenty-seven clients (69%) took advantage of this service. With the exception of one caregiver all found the transportation provided was very helpful. Six caregivers stated that transportation was essential for client participation. Two caregivers said they were too far away to use the service and one was unaware of the service.

Table 9 Program Components Provided to Clients/Caregivers

Program Components	% Used or Rec'd Service (n=44) n (%)	Helpfulness of Service Provided Scale Ratings +									
		1 n (%)	2 n (%)	3 n (%)	4 n (%)	5 n (%)					
Transportation to DA program	27 (69)*	1 (4)	—	—	3 (11)	23 (85)					
Respite care at home	12 (27)	—	—	1 (8)	1 (8)	10 (83)					
Information re Alzheimer Dis.	29 (66)	1 (3)	—	4 (14)	7 (24)	5 (59)					
Info. re Other Services Available	31 (71)	1 (3)	1 (3)	5 (16)	7 (22)	18 (56)					
Info. re Legal/Financial Matters	16 (36)	—	1 (6)	1 (6)	8 (50)	6 (38)					
Counselling & Support	32 (73)	—	1 (3)	5 (16)	5 (16)	21 (66)					
Caregiver Diary	29 (74)*	1 (3)	3 (10)	5 (17)	9 (31)	11 (38)					
Family Support Group	15 (34)	—	—	5 (33)	1 (7)	9 (60)					
Services Related to Clients Physical Health	20 (46)	—	2 (10)	4 (20)	7 (35)	7 (35)					
Overall Day Away Program	39 (100)*	4 (10)	—	3 (8)	1 (3)	31 (80)					

*based on Day Away clients only n = 39

+ 1 = not at all helpful
3 = somewhat helpful
5 = extremely helpful

ii. Respite Care at Home

In cases where other services such as Chronic Home Care were not currently available to clients, staff provided respite care for clients at home. Twelve caregivers (27%) were provided with this service; all but one found this service very helpful. Three respondents were unaware of this service.

iii. Information Services

A component of program service was the provision of up-to-date, relevant information to caregivers on Alzheimer's Disease, other services available in the community and legal and financial matters. Caregivers receiving this service rated the helpfulness of the information as follows:

1. Information re Alzheimer's Disease: Information on the disease process prepares the caregiver for what to expect as the client enters each stage of the disease. Two-thirds of caregivers were provided with this type of information. Most respondents (83%) found this information very helpful.
2. Information re Other Community Services: Caregivers are assisted in seeking and qualifying for other services. Thirty-one (71%) caregivers received this information; 78% of these caregivers found it very helpful.
3. Information re Legal/Financial Matters: Caregivers are provided with information on legal aspects concerning themselves and the client, e.g. power of attorney, Public Trustee Act. Sixteen

respondents received this type of information; 88% indicated it was very helpful.

Caregivers were asked if they were given the opportunity to talk to staff about difficulties in caring for a person with Alzheimer's Disease. Seventy-three per cent indicated that they had received counselling and support from staff. Eighty-two per cent rated counselling received as very helpful. Two respondents would like to be able to discuss concerns in French.

iv. Caregiver Diary

A diary is set up for Day Away program clients in which caregivers are encouraged to record any problems and/or successes they have with the clients at home during the week. In turn, program staff record each client's development in the diary on the day they attend the program. The diary has a dual function as a means of expression for the caregiver and a means of providing continuity of care between the program and the home setting.

Three-quarters of caregivers reported that they used the caregiver diary. Sixty-nine per cent of those who used the diary found it was very helpful. Two caregivers were unaware of the diary.

v. Family Support Group

Family Support Groups are available to the membership of the Société Alzheimer Society of Ottawa-Hull and the general public as well as the Programs' caregivers. They are offered under the auspices of the

Home Assistance Program. Family Support Groups through the guidance of the family support worker can evolve into self-help groups. The group objectives are to provide a supportive atmosphere in which information can be shared and mutual support given.

One-third of respondents indicated they had participated in a Family Support Group. Sixty-seven per cent who took part in this activity found it very helpful. Ten respondents indicated that family support groups scheduled in the evenings were inconvenient. Many were either unable or unwilling to go out at night. One respondent reported he/she had gone to one meeting but received no follow-up on further meetings. Another caregiver found the group so helpful, she set one up herself with assistance from the Family Support Coordinator. One respondent was unaware of the groups.

vi. Services Related to Clients' Physical Health

Staff assisted caregivers by providing services related to the client's physical health. Assistance in monitoring clients' medications, blood pressure, and weight are examples of this type of service. Twenty clients received this type of service. Seventy per cent found this service very helpful.

Summary

Caregivers indicated they were extremely well satisfied with the various components offered by the programs. Services most used by caregivers were transportation to the Day Away Program, information on Alzheimer's Disease and on other community services available,

counselling and support and the caregiver diary. Service least used was Family Support Groups. This may be due to the unavailability of day time meetings.

Two-thirds or more of the caregivers who indicated they had used various services rated those services as very helpful, i.e. gave them a rating of 4 or 5. Caregivers with clients in the Day Away Program found the program beneficial both for themselves and the clients.

c. Service Provision: Individual Management Plans

Clients have individual plans designed to meet their individual needs. Plans are aimed at addressing client/caregiver problems and family needs by providing programs suitable to the client's abilities. Caregivers were asked if they had received assistance with any problems specific to the client in several areas.

Individual Management Plans

- | | | |
|----------------------------|---|---|
| Recreational | - | a recreational plan can be developed appropriate to the client's capabilities |
| Activities of Daily Living | - | step-by-step breakdown of tasks to help client understand and complete a self-care or household task to the best of his/her ability |
| Communicating | - | techniques designed for caregivers to improve client's receptive and expressive language skills |
| Exercise | - | exercise regime to promote mobility, strength and body awareness within the limits of the client's ability |

- Memory Problems - techniques for caregiver to maximize the client's ability to recall and minimize client's frustration resulting from his/her inability to recall
- Nutrition - dietary programs and aids which ensure client's nutritional requirements are met
- Behaviour problems - caregivers are taught how to deal with problematic client behaviours
- Other - caregivers indicated they had received assistance with client placement in an institution; engaging help in the home; arranging for medical assessments and evaluation; linking up with community services and other Alzheimer's couples.

Table 10 presents data on the percentage of caregivers who were provided with specific plans in each area and the degree of helpfulness these services provided on a scale of 1 to 5. All caregivers received specific plans in at least one of the areas listed. The majority of respondents found these plans very helpful.

d. Referrals

Caregivers were asked to indicate any services to which they had been referred by the programs. Table 11 presents type of services referred to and respondents' rating of their helpfulness. Thirteen (30%) were referred to the Home Care Program. Home Care provides professional services: e.g. nursing, occupational therapy, physiotherapy and non-professional services, e.g. homemaking in the home to those who meet their criteria. Seventy-seven per cent of clients referred to this service found it very helpful.

Clients/caregiver were also referred for respite care (3 referrals), assessment and placement services (4 referrals each). Most

Table 10 Individualized Plans Provided to Clients/Caregivers
for Specific Problems

Services Re Client-Specific Problems	Caregivers Rec'd Services (n=44) n (%)	Helpfulness of Service Provided Scale Ratings									
		1 n (%)	2 n (%)	3 n (%)	4 n (%)	5 n (%)					
Recreational Activities	20 (46)	1 (5)	—	4 (20)	4 (20)	5 (55)					
Activities of Daily Living	20 (46)	—	1 (5)	5 (25)	5 (25)	9 (45)					
Communicating	20 (46)	1 (5)	—	1 (5)	7 (35)	11 (55)					
Exercise	14 (32)	—	1 (7)	4 (29)	4 (29)	5 (36)					
Memory Problems	18 (41)	—	1 (6)	4 (22)	4 (22)	9 (50)					
Nutrition	17 (39)	—	1 (6)	5 (31)	3 (19)	7 (44)					
Behaviour Problems	14 (33)	—	—	3 (21)	4 (29)	7 (50)					
Other	17 (39)	—	—	2 (12)	3 (18)	12 (71)					

* 1 = not at all helpful
3 = somewhat helpful
5 = extremely helpful

Table 11 Services to Which Clients/Caregivers Were Referred

Type of Service	Number Referrals (n=44)	Helpfulness of Services Scale Ratings				
		1	2	3	4	5
Respite Care	3	-	-	-	-	3
Assessment	4	-	1	-	1	2
Placement	4	1	-	-	-	3
Home Care	13	1	1	1	2	8
Other	4	1	-	1	-	2

* 1 = not all helpful
 3 = somewhat helpful
 5 = extremely helpful

respondents were satisfied with these referrals. "Other" referrals included one to Quebec Social Services (CLSC), the Quebec equivalent of the Home Care Program; one to a nutritionist; and two to a chiropody clinic.

e. Caregiver Expectations and Program Satisfaction

Caregivers were asked if the program they received had met their expectations. Forty (91%) replied that it had met their expectations; one person felt that it hadn't; and three were uncertain.

Caregivers commented that the programs were enjoyable, helped to relieve feelings of helplessness and provided the support which was needed. The Day Away Program gave clients an opportunity to get out and meet people, which was particularly important for those with no other social resources.

Caregivers were requested to rate their overall satisfaction with the service they received on a five point scale. Overall satisfaction with the program was high. Ninety-five per cent of respondents were very satisfied, i.e. rated the program 4 or 5 on the scale, while only two respondents indicated they were somewhat satisfied.

f. Problems Experienced in Service Delivery

Most caregivers did not cite any problems with service delivery. Three respondents had experienced what they considered too long a period of time between their first contact with the program to actually being admitted or receiving service. Three respondents referred to

communication problems between themselves and staff members in regard to re-admission to the program.

Three respondents indicated that transportation provided to the Day Away Program was problematic. They felt that the bus came too early in the morning, the trip took too long and that availability of the service was limited.

Two caregivers felt that more availability of French-speaking staff would have helped to reduce client anxiety in one case and have been helpful to the client's spouse in another.

Individual problems mentioned by caregivers included:

- lack of available parking at Elisabeth Bruyère; respondent suggested short-stay parking for picking up and dropping off clients
- one month advance billing was inconvenient
- initial difficulty in finding information about the program
- client was unable to remain in program because he was frightened by others with more advanced dementia.

g. Caregiver Recommendations

Caregivers were requested to give any comments on the services they received and suggestions for program improvement. Following is a summary of their comments and recommendations.

Public education/publicity

Education of the general public, families of Alzheimer's victims and physicians was considered important by seven respondents. It was stressed that families of Alzheimer's individuals must be educated in

the progression of the disease, so they can prepare for the type of care and support they will need. Information packages on the nature of the disease and services available should be made widely available. Respondents felt the Day Away Program should be publicized more to assist in fund raising and community awareness.

Home Assistance Program

In general, those who commented on the Home Assistance Program felt it should be expanded. It was suggested that the number of home visits be increased in order to: 1) assist in training of other service providers; 2) give more help to caregivers who are on their own; 3) assist with activity programs in the home. Staff should maintain contact and support to caregivers and Day Away staff should make more home visits.

Day Away Program

Four respondents felt the Day Away Program should expand both its current services and expand into new areas. Four respondents would like both hours of service and number of days service is provided increased. Comments on program location included a suggestion to rotate the program in clients' homes to provide a home rather than an institutional setting. Another suggested movement to a larger facility so that more people could benefit from the service. It was suggested that Day Away extend its mandate to provide both overnight respite care and respite care for those awaiting facility placement. It was recommended that the

program be modified in two phases which would include an initial program, in which thorough assessment of the client can be made, followed by a mainly social program which could be attended more frequently.

Two caregivers indicated that the Day Away Program could be improved by providing more recreational activities geared to men. Individual suggestions for program improvement included musical concerts; a rest period with proper resting facilities; indoor activities other than crafts; films. One respondent felt outings improved the program, while another thought long outings or rides were unsuitable for clients.

Community services

Respondents indicated ways in which the program could help improve community services for Alzheimer's individuals and their caregivers. Suggestions included: a report on local institutions and the services they provide; approach community services which provide sitters to include Alzheimer's individuals among their clientele; augment family support groups by providing video/audio cassettes; conduct family support meetings during the day; and lobby the government to provide more short respite accommodation.

Staff/Client/Caregiver Relations: Two caregivers suggested that staff should not telephone the family, if the client became agitated or unhappy. They felt staff should be able to calm the client through reassurance. Individual suggestions for improvement of staff, client

and caregiver relations included: caregivers should explain to staff which activities the client will and will not enjoy; match clients appropriately, e.g. a talkative client paired with another with limited expressive ability; separate clients based on degree of dementia.

Staffing: Three respondents commented on current staffing arrangements. Respondents suggested that more French-speaking staff be available; that a "task force" responsible for recruiting volunteers be established, and that only one professional on staff was necessary.

Language: One respondent felt that clients should be dealt with in their first language and another commented that there was a need for French Family Support Groups.

Caregiver Support: Respondents made suggestions on how support to caregivers could be improved. Five comments were made on the need for more care and support in the home, including more home visits for those in the Day Away Program, more respite care providing both supervision and companionship, assistance with accessing more service through the Home Care Program and an emergency contact person on call for caregivers.

It was expressed by three respondents that caregivers need more opportunities to get together informally, rather than just through structured meetings. The programs should provide more opportunities for caregivers to socialize before and after the Day Away Program in order to get to know staff and other caregivers.

h. Facility Placement Status of Clients

The majority of clients were not on any waiting lists for facility placement when they entered the programs. Thirteen clients had been placed in facilities since admission to the programs and six clients who were still living in the community had been on waiting lists since before program participation and are currently still on waiting lists for placement. Two clients were deceased.

The six cases who were on waiting lists prior to program admission can be seen as those for whom institutionalization was a serious consideration for some time. Thus, in order to assess program impact, these six respondents were asked if they would accept facility placement for the client if it was offered now. Four caregivers responded that they would not accept placement if it was offered at this point. They felt that delaying of institutionalization of the client was important and that adequate support was being provided to allow them to maintain the client at home. Two caregivers stated they would accept placement for their family member if offered now. One feared that if she refused placement now her name would be put at the bottom of the list. The other respondent indicated that the recent rapid degeneration of the client necessitated immediate placement.

i. Other Support

To assess the impact of services other than those provided by Home Assistance and Day Away, caregivers were asked to describe other professional services received as well as support from family members

and friends. Respondents were questioned about the adequacy and availability of these forms of service and support. Information on support services was only collected from respondents who at present have clients living at home (n=29).

Twenty-five caregivers (86%) who still had Alzheimer's family members at home, received professional service other than the programs. Table 12 presents the type of services received and the number of respondents receiving them. Some caregivers may have received more than one service. Nursing care provided by the Victorian Order of Nurses (VON) as part of the Home Care program was received by eleven clients. Clients were typically visited once a week. Homemaker services through Home Care and privately were provided to eight clients. These services were provided from one to three times per week and approximately three hours per visit. Eleven caregivers indicated that they had hired sitters to provide routine care and supervision for the clients on a regular basis.

Twenty-six caregivers (90%) received some support from family, neighbours or friends. On average caregivers received visits from relatives and/or friends once or twice a week.

All respondents received some support from at least one source. Most caregivers (76%) felt that the support and services they received were adequate to enable them to care for their family member at home. Of those who felt support services weren't sufficient, four indicated they needed more respite care for the client and two required more homemaker service.

Table 12 Professional Services Received by Caregivers

<u>Service</u>	<u>Number Receiving Services</u>
Victorian Order or Nurses (VON)	11
Homemakers (private and through Home Care)	8
Hired sitter/caregiver	11
RNA	3
Regional Health Nurse	1
Physiotherapist	1
Occupational Therapist	1
Meals-on-Wheels	3
Social Worker/Counsellor	3
Home Care (specific service not given)	6

To determine if those seeking services for Alzheimer's Disease individuals had encountered any special difficulties in accessing services, respondents were asked if they were ever denied services which they had requested and the reasons for refusal of service.

Twenty-four respondents (83%) had not been refused any services which they had requested. Of the five who indicated they were denied service, reasons were related to the particular problems which Alzheimer's Disease individuals and their family members confront. In one case Chronic Home Care was denied because the client had no physical ailment, and in one case occupational therapy through Home Care was withdrawn due to client non-compliance. One caregiver was denied a request for hospital placement for a client who repeatedly fell out of

bed; and a retirement home sent a client back to the family, because of Alzheimer's Disease. Although most clients were not denied service, refusal of service was associated with an inability or unwillingness to meet needs of Alzheimer's clients.

j. Changes in Perceptions of Family Burden

Many factors may impact upon a caregiver's ability to maintain the client in the home. Changes in personal, financial, health and family situations may effect the degree of burden the caregiver experiences. Changes in family burden as measured at program intake and at six months follow-up have been analysed as the principal measure of outcome in this evaluation. To augment this outcome analysis, caregivers were asked to comment on any factors in the last six months which have affected the burden associated with care of the client.

Twenty-one respondents (72%) found that taking care of their family member had become more difficult during the past six months. All but one caregiver attributed this increased difficulty to the progression of the disease. The other most frequently cited reason (nine cases) for increased difficulty in providing care at home was either illness or disability in the client or caregiver, which in a few cases was made even more problematic by a decrease in support from other family members.

Five respondents felt there had been no change in the amount of difficulty associated with care of their family member, and three felt burden had decreased. Those for whom burden had decreased attributed

the change to a combination of the Day Away Program and an increase in caregiver relief from other sources.

Summary of Results

1. Thirty-two (83%) caregivers of relatives who had received the Day Away Program rated it very helpful. Caregivers indicated that the program was beneficial to themselves as well as the clients.
2. Caregivers were extremely well satisfied with the various program components. Transportation to Day Away, information provision, counselling and the caregiver diary were the services most often used. Family Support Groups were least often used by caregivers.
3. All caregivers received specific client-oriented management plans. The majority found these programs very helpful.
4. Thirty-one referrals to other services were made by the programs for clients/caregivers. Most referrals were to the Home Care Program. Satisfaction with referrals received was high.
5. Most caregivers experienced no problems with service delivery from the programs. Some respondents expressed difficulties with hours of service, limousine service, delay in admission to program.
6. Caregivers recommended ways in which service could be improved. Suggestions addressed accessibility, hours of service, caregiver/client/staff relations, staffing, language, caregiver support and transportation.
7. Six clients were on waiting lists for institutional placement. Four caregivers indicated they would not accept a placement if offered one at this point. They felt that institutionalization should be delayed as long as possible and that sufficient supports were currently in place to allow them to maintain the client at home.
8. All caregivers who still have clients living at home had some support either professionally or through family or friends other than service they received from the programs.
9. Most caregivers felt support services they received were adequate. Of those who felt support was not sufficient, respite care and homemaking were the services most often lacking.
10. Most respondents had not been denied services they requested. Those who were denied service associated the refusal with problems specific to Alzheimer's individuals.

11. Twenty-one caregivers (72%) reported that taking care of their family member had become more difficult during the past six months. Most caregivers cited progression of the disease and/or illness of caregiver or client as the reasons for increased difficulty. For eight caregivers burden had remained the same or decreased. Decreased burden was attributed to the Day Away Program and more support from other sources.
12. Caregivers felt the programs could provide better service to Alzheimer's individuals and their caregivers through more public education and publicity; increase in home visits; expansion of Day Away Program; assessment of community services; informal caregiver support networking; day time and French Family Support Groups.

Discussion

Caregivers expressed a high degree of satisfaction with the services the program provided. Caregivers also received services and support from other professionals and family and friends.

Four of the six respondents who had family members on waiting lists since before program admission indicated they would not accept placement if it was offered now. In three cases, burden to caregivers was reported to decrease and in five cases it was maintained at a manageable level during the past six months. In all these cases, the Day Away Program played a part in the support network for caregivers which enabled them to keep their family members at home.

3. Staff Perceptions of Program Operation

A personal interview was conducted with all paid staff of the Day Away/Home Assistance Programs and with the unpaid volunteer coordinator.

Staffing

Four of the seven staff members are full-time. Distribution of responsibilities between the two programs varies by staff member. Program staffing is summarized in Table 13.

Table 13 Professional Staffing of the Day Away/Home Assistance Programs

<u>Staff Member</u>	<u>Full time/part time</u>	<u>% H.A.</u>	<u>% Day Away</u>
Program Director (R.N.)	full time	36	64
Assistant Program Director (R.N.)	full time	-	100
Family Support Co-ordinator	full time	40	60
Social Worker	full time	40	60
Occupational Therapist	70% time	30	70
R.N.A.	50% time	100	-
Recreologist	50% time	100	-

Six of these staff had previous experience working with Alzheimer's clients prior to joining these programs. Five staff had contributed their time to the Day Away Program prior to funding when it operated as a volunteer program.

Staff were asked if the current complement is adequate to provide a high quality service. Only one staff person responded yes. Additional professional staff were seen as required to improve service and to allow for a rearrangement of current staff between programs. Several new staff positions were recommended and these included:

- a) a neuropsychologist on a fee-for-service basis in order to conduct assessments and interpret results. The waiting period for diagnosis was reported to be one month or more,
- b) more full-time professionals in Day Away to free the occupational therapist, social worker and family support coordinator to use their expertise in the community,
- c) an R.N. to conduct assessments of medical problems for clients in Home Assistance,
- d) a paid coordinator of volunteers,
- e) a clerk-stenographer.

As can be seen in Table 13, the Day Away Program has one full-time staff member and three part-time treatment staff who share their time with the Home Assistance Program. Staff members recommended separate and distinct staffing for these two programs. This change was seen as a way of increasing the continuity of care and eliminating the need for staff to change their roles.

Staff offered a number of alternative staffing options given the reassignment of part-time Day Away staff to Home Assistance:

1. An additional full-time professional in the Day Away Program who would be responsible for the Day Away Program in the absence of the Assistant Program Director. In addition, two full-time R.N.A.'s to replace the occupational therapist, social worker and family support coordinator who would be assigned to the Home Assistance Program while assuming consultative roles to the Day Away Program. The two programs would, therefore, have separate staffing, but would share expertise on a consultative basis.
2. Two additional full-time staff in the Day Away Program, with Home Assistance staff attending Day Away as required to settle their clients newly admitted to the program. This would allow Home Assistance workers to retain their skills working with clients.

3. The Assistant Program Director plus a pool of volunteers with professional backgrounds. It was suggested that the more effective use of volunteers should be examined.

Despite the perceived need for additional staff, six of the seven staff members felt caseloads were not too large. The programs are, however, currently restricting the numbers of new cases in order to maintain manageable caseloads.

Staff development

With the opening of a Monday morning day program and the use of Monday afternoons to complete home assessments, staff development and program development activities have been largely limited to Fridays. Staff development activities include guest speakers, discussion of new research findings and community programs. Staff also attend in-service programs, symposia and conferences.

Staff were asked if they had sufficient time for staff development. Four responded yes, while three responded no. The two half time members indicated time restrictions made participation difficult.

Service Provision

Staff were asked which services of the programs they felt essential to assist clients to live in the community. The only program component uniformly mentioned was respite. It was commented that if caregivers are unable to obtain respite, both client and caregiver may deteriorate. It was emphasized that the caregiver must maintain himself in order to continue caring for the client.

Other program components mentioned as being essential by some staff were the day program, including transportation to Day Away; counselling and support; information regarding Alzheimer's Disease and available community resources; activities of daily living programming; management of behaviour and memory problems; and communication techniques. It was mentioned by several staff that the complete menu of program components is not served to all families. Clients and caregivers vary in their needs and in the amount of information and assistance with which they are able to cope.

Program components frequently mentioned as less essential were legal and financial information, caregiver diary, exercise, nutrition and recreational activities.

Community Liaison

Community liaison, i.e., management of community referrals to other agencies, is an important aspect of program staff's work. Staff were asked if any gaps in service had been found in seeking referrals for clients. There were several gaps identified. Gaps were seen particularly for clients in early stages of the disease and those requiring placement.

Homemaking through Chronic Home Care is not available if the need for services of a professional three times per month cannot be identified. Respite for caregivers of ambulatory Alzheimer's individuals is not available. Home support services that are financially accessible to caregivers are difficult to find. Several agencies have refused to accept a referred client. These agencies

include long term care facilities, chronic home care, and day care facilities. In most cases in which a client has been refused, the service has been unable to manage the Alzheimer's client.

Community Services

The only service reported by all staff members as essential to the operation of Day Away/Home Assistance Programs was a diagnostic clinic. Most staff felt that Chronic Home Care would also be a requisite service to operate these programs. Other services frequently mentioned included: a placement coordination service, a family medicine unit and a committed group of volunteers. While the programs were viewed as most appropriate for large centres, a modified version of the programs could be established in smaller centres, using existing health and social services available in a community.

Alternatives

Several alternatives were suggested in order to improve services to clients and family caregivers.

Staff recommended a two phase approach to service delivery. The current highly technical team of professionals would provide an eight-week acute assessment program in order to determine needs and establish treatment plans. Once a management plan was established, clients would be transferred to an existing program or to a structured satellite day program. The core assessment team would provide satellite day programs with assessment results and individual management plans.

This two phase approach was seen as a way of separating responsibility for short-term assessment and longer-term maintenance. The latter was seen as appropriate for less technical staffing, including a coordinator, R.N.A. and volunteers.

This change would see an acute assessment unit operating as a "flow-through" unit. It was stated that a larger client population would then be feasible. Satellite programs would also be available to clients for whom transportation has been a problem.

Several staff members referred to the current policy of restricting admission to Alzheimer's individuals. Three staff members felt the programs should provide service to individuals with other forms of dementia. One staff member indicated the current policy should continue.

The volunteer coordinator expressed the concerns of volunteers in two areas. There are no clear guidelines setting out the limits of activities delegated to volunteers. Volunteers work side-by-side with staff and accept increased responsibilities when staff temporarily leave the program. This lack of clear guidelines may have legal implications. Given the extent of their involvement in the program, volunteers are concerned that there is no group liability coverage for volunteers.

4. Community Agency Survey

In the increasing network of services available to the geriatric population, any new agency or program should be examined to determine the degree to which it has become integrated into the service network and to what degree it fills a gap in service delivery for its particular

target group. In order to obtain this information, agencies which were known to serve Alzheimer's individuals and their caregivers were surveyed. Questionnaires addressing referral patterns, program satisfaction, service overlap, and target group served were mailed to the following agencies and institutions:

1. Queensway Carleton Day Hospital
2. Geriatric Assessment Clinic, Ottawa Civic Hospital
3. Alzheimer and Memory Disorder Clinic, Ottawa General Hospital
4. Dept. of Psychology, Elisabeth Bruyère Health Centre
5. Societe Alzheimer Society of Ottawa-Hull
6. Ottawa General Psychogeriatric Clinic
7. Elisabeth Bruyère Day Centre
8. St. Patrick's Home for the Aged
9. Placement Co-ordination Services of Ottawa-Carleton
10. Chronic Home Care Division, Ottawa-Carleton Regional Health Unit
11. St. Vincent's Day Hospital

Ten agencies (91%) returned completed questionnaires. Seven agencies indicated that they both received and made referrals to the program, while three agencies only referred to the program. Six agencies indicated that they hadn't encountered any problems with referrals between themselves and the program. Problems experienced by the other four agencies included: lack of feedback provided to the physician on a decision to accept or refuse a referral; too long a waiting period for assessment and admission to program; lack of understanding of other agency's admission criteria; and exclusion of individuals with other types of dementia.

Respondents were requested to indicate what referrals or arrangements were made by their agencies for clients with Alzheimer's Disease, prior to the existence of the Day Away/Home Assistance Programs and to indicate their satisfaction with these services. Agencies

indicated that before the establishment of the programs, referrals for Alzheimer's Disease individuals were made to seniors' day centres, day hospitals, and home services such as Home Care and private homemaking agencies. Difficulties were often encountered by Alzheimer's referrals not meeting eligibility criteria for day hospitals and home care. As well seniors' day centres were only able to accommodate those Alzheimer's clients in the early stages of the disease. Clients were also referred for psycho-geriatric assessment and treatment, and these services did not provide on-going follow-up or family support and education. In general, it was held, that prior to the Day Away programs there was little available in Ottawa and the surrounding areas for respite care of Alzheimer's individuals other than crisis intervention and emergency institutional placement. Most agencies indicated that they continue to make referrals to the above mentioned sources when deemed appropriate for their Alzheimer's clients.

Services provided by these agencies to Day Away/Home Assistance clients included: therapeutic services, e.g. occupational therapy, physiotherapy; assessment, e.g. neurological, psycho-geriatric; counselling; social work; education; and advocacy. When asked to rate service provision at the Day Away/Home Assistance Programs, seven agencies rated the programs very good or excellent, one rated them as satisfactory and two refrained from rating the programs.

Agencies provided suggestions on ways in which program service could be improved. Expansion of services in terms of increases in staffing, funding and number of program sites were most often mentioned.

Two agencies suggested inclusion of clients with other forms of dementia in program services. Single suggestions included better working relations with other agencies which provide service through understanding of agencies' capabilities and limitations; and an evaluation of the total amount of assessment a client undergoes to determine if clients are given more than they can handle.

Respondents rated on a five-point scale the need for therapeutic day care and home assistance for Alzheimer's Disease clients exclusively, in Ottawa-Hull. All respondents, but one, felt the need for these specialized services was very high. To further assess need for service, respondents were also asked if designation of separate programs to provide day care and home assistance for Alzheimer's individuals and their caregivers represented an overlap of service. All agencies agreed that there was very little overlap between the programs' services and other community services.

Agencies expressed a great deal of satisfaction with the programs and felt they filled an important gap in the community. Referral relationships between the programs and other agencies were considered very good. One agency indicated that it was currently working with the programs to provide jointly planned services to clients and families in need, to ensure any overlap of service was eliminated. Changes mentioned which could improve program services were expansion of programs to serve more clients in more locations, the addition of in-home respite care and the inclusion of those with other forms of dementia in the programs.

V. OUTCOME ANALYSIS

Family burden was chosen as the primary measure of program outcome. It was hypothesized that family burden significantly influences whether an Alzheimer's individual will continue to be accommodated within the family home. Burden has been shown to be a subjective experience associated with the caregiver's ability to tolerate and cope with problems. Thus, an increase in burden increases the likelihood of early institutional placement. Burden is also closely associated with the level of dementia of the Alzheimer's individual. Rapid deterioration of the affected individual will, in most cases, bring about a concomitant increase in burden. The purpose, therefore of this analysis is to examine the relationship between level of dementia and burden and to assess the degree to which the program intervention can affect feelings of burden among caregivers.

Lastly, cost comparison data have been presented for the programs and institutional care. For cases in which delayed institutionalization of clients can be identified, these cost figures can be used to estimate savings.

A. Client Outcome

All clients who had been or were currently involved in the Day Away/Home Assistance Programs from January to July 1985 who had a caregiver able to participate in a personal interview were included in the outcome study. Of 45 eligible participants, personal interviews were conducted with 44 caregivers.

Program staff administered the Hierarchic Dementia Scale and the Family Burden Index at intake and at six month follow-up. The Hierarchic Dementia Scale (see Appendix D) measures severity of dementia and includes measurements of cognitive, language, perceptual, motor and memory abilities. It consists of 20 functional hierarchies of mental abilities which are scored from 0 to 10. Items are totalled to yield a score out of a possible 200 points. The lower the score, the more severe is the dementia.

The Family Burden Index (see Appendix D) provides a measure of the level of stress the caregiver is experiencing. The instrument consists of 22 items which are rated on a scale of 0 to 4 by caregivers. Items are totalled to yield a score out of a possible 88 points. The higher the score, the more stress the family is experiencing. The Family Burden Index was left with the caregiver to complete and return to the program.

The caregiver interview was completed in 44 cases. Administration of the Hierarchic Dementia Scale and Family Burden Index to study participants, however, was dependent on a number of factors as indicated in Table 14. Of the 44 study participants 26 clients continued to live in the community over the entire six month follow-up period. Complete data were available on 18 clients and their caregivers. In two cases, follow-up was due, but data were not collected in time for inclusion in the study. In these two cases, caregivers failed to return the Family Burden Index. In six cases, the Hierarchic Dementia Scale was not

Table 14 Data Collection of Hierarchic Dementia Scores
and Family Burden Index (n=44)

	<u>no. of study participants</u>
I Client living in community over entire 6 month follow-up period (n=26)	
1. Complete data available	18
2. Follow-up due but unable to collect data	2
3. Hierarchic Dementia Scale not administered due to anticipated negative effect of testing	6
II Client no longer living in community (n=12)	
1. Client placed prior to follow-up	10
2. Client died prior to follow-up	2
III Client living in community less than 6 month follow-up period (n=6)	
1. Follow-up not yet due; clients involved with program 3 to 4 months	6

readministered as program staff felt the client would react poorly to a testing situation.

The Hierarchic Dementia Scale could not be readministered in 12 cases, as these clients were no longer living in the community at six month follow-up. Ten clients had been placed in a facility prior to follow-up. It was beyond the scope of this evaluation to negotiate with facilities to conduct follow-up with these clients. Caregivers of these clients were, however, interviewed to gain their perspective of the usefulness of the program during the client's involvement with the programs and during the placement process. Two clients had died. In six cases, follow-up was not yet due, i.e., clients had been involved with the program for only three to four months.

Clients who were living in the community over the six month follow-up period ($n=26$) were compared with clients who were no longer living in the community ($n=12$) on measures of dementia and family burden at intake. Clients maintained in the community had a mean intake score of 125 on the Hierarchic Dementia Scale compared with a mean of 105 for clients no longer living in the community. The lower the score, the greater is the dementia. For both groups, the standard deviation was 34. It was therefore, those clients with the lowest dementia at intake who were maintained in the community over the six month follow-up period. Those with the highest dementia at intake were placed or had died over the six month interval. A t-test conducted on these scores ($t=1.65$; $df=35$; $p<.10$) revealed that this observed difference has a .10 probability of occurrence in the absence of a true difference. In

applied research, $p < .10$ is frequently used as an appropriate level of significance. During communication with one of the authors of the Hierarchic Dementia Scale, it was learned that a change of 10 points on the scale indicates a change in functional abilities. The 20 point difference obtained between the two groups is, therefore, a substantive difference.

Clients maintained in the community were also compared with those no longer living in the community on family burden at intake. Those maintained in the community scored a mean of 39 compared with a mean of 48 for those placed in an institution on the Family Burden Index. Families of clients who were placed or had died had experienced greater burden at intake than families of clients remaining in the community. This difference was significant ($t = -1.91$; $df = 33$; $p < .065$) at the .10 probability level.

The mean dementia score at intake for those who were institutionalized was somewhat lower than the mean dementia score at intake for those who remained in the community. In order to test how strong the relationship between these variables was a point biserial correlation coefficient was calculated.

The correlation coefficient of .27 shows a weak correlation between dementia score at intake and institutionalization during the follow-up period. That is, it is not possible to predict with confidence institutional placement on the basis of dementia scores at intake.

In order to test the strength of association between family burden at intake and institutional placement during the follow-up period a point biserial correlation coefficient was calculated.

The correlation coefficient of .31 shows a weak relationship between family burden score at intake and institutional placement. As with dementia at intake, while there is a relationship it is a weak one which does not well predict the likelihood of institutional placement.

The major program outcome measure of change in family burden was based on the 18 cases for whom complete data were available. All 18 cases had attended the Day Away Program. Home Assistance only clients were not represented. All clients for whom complete data were available were living in the community at six month follow-up. Those no longer living in the community were not represented. These clients were less demented and their families were less stressed than clients no longer living in the community.

A paired t-test was conducted comparing intake scores on the Hierarchic Dementia Scale with six month follow-up scores. Over the six month follow-up period, clients' dementia had significantly increased ($t=2.89$; $df=17$; $p<.01$) from a mean of 130 points at intake (standard deviation of 36) to a mean of 119 points at follow-up (standard deviation of 44). All clients but two had deteriorated according to the dementia scale. The mean increase among those who had increased in dementia was 14 points, ranging from 3 to 45 points. One-half of these clients deteriorated 10 or more points, indicating a change in functional abilities. Clients who were maintained in the community over

a period of six months had significantly deteriorated over the duration of the follow-up period.

Change scores on family burden were calculated for each study participant from the Family Burden Index scores collected at intake and at six month follow-up. A paired t-test comparing intake scores with six month follow-up scores revealed no significant difference ($t = -.18$; $df=17$; $p<.85$). Caregivers scored a mean of 38 points at both periods of data collection. The program was, therefore, unable to significantly reduce the stress caregivers were experiencing at program intake. As Alzheimer's Disease is a chronic, degenerative condition, maintenance of family burden has also been considered a positive program effect. This analysis indicates that the program was successful in maintaining family burden despite a significant increase in severity of dementia. That is, burden did not significantly increase as dementia significantly increased.

Table 15 shows that in 12 of 18 cases (66%), family burden had either decreased or was maintained. For purposes of this study, a change score of plus or minus two points was considered no change. In six cases burden increased more than two points.

Table 15 Changes in Family Burden at 6 Month Follow-up

<u>Change</u>	<u>n</u>
1. Decrease in burden	7
2. No change in burden	5
3. Increase in burden	6

As Alzheimer's individuals tend to deteriorate over time, the effect of this disease process on the client's condition and consequent changes in burden had to be considered. That is, an increase in burden may be related to rapid deterioration of the client's condition and be unrelated to the program. The Hierarchic Dementia Scale and Family Burden Index were administered concurrently which enabled an assessment of the effect of the disease process.

As no norms exist as to what degree an Alzheimer's individual may deteriorate over time, the mean dementia change score for study participants was calculated and used as a baseline against which to compare dementia change scores in individual participants. In those cases in which an increase in burden was observed, the dementia change score was compared with the mean change in dementia. As shown in Table 16 there are three possible burden outcomes. Group 1 represents the positive outcome for the program in that burden has been maintained or decreased. For this group, change in dementia need not be considered as decrease or maintenance of burden is viewed as a positive outcome. In 12 cases (66%), program effect was positive. Group 2 represents a negative outcome for the program. This group consists of those cases in which burden increased and whose dementia change score was less than or equal to the mean dementia change score for the study sample. In only three cases (17%) was there a negative program effect. The factors contributing to increase in burden in these three cases are unknown. Group 3 is composed of those cases in which burden increased and whose dementia change score was greater than the mean dementia change score. For this group, it is assumed that increase in burden was due primarily

Table 16 Program Outcome on Family Burden Controlling for
Increase in Dementia (n=18)

	<u>Group</u>	<u>%</u>	<u>Outcome</u>	<u>Burden</u>	<u>Dementia</u>
1.	n=12	66%	Positive	Maintenance or decrease	Not controlling for dementia
2.	n=3	17%	Negative	Increase	Less than or equal to mean change score
3.	n=3	17%	Neutral	Increase	Greater than mean change score

to an increase in dementia. In 3 cases (17%), the program effect has been considered neutral, given the increase in dementia.

Cases in which burden was maintained or decreased were compared with the six cases in which burden increased. There were, however, no differences apparent in age of caregiver, caregiver satisfaction with the program, number of weeks in the program, community supports, or caregiver's perception of the adequacy of community support.

The Day Away Program reduced or maintained the level of family burden in two-thirds of families who had a relative with Alzheimer's Disease living in the community. The program was successful in assisting these families in maintaining the client in the community in light of the fact that clients significantly increased in dementia over the six month follow-up period. Whereas dementia significantly increased, there was no concurrent significant increase in family burden.

Summary of Results

1. Two-thirds of clients associated with the program over a six-month period continued to live in the community, while one-third were no longer living in the community at six month follow-up.
2. While both family burden scores and dementia scores at intake were related to the likelihood of institutional placement, these relationships were weak, ($r=.31$ and $r=.27$ respectively) and therefore have little predictive power.

3. Dementia significantly increased for the clients remaining in the community for whom complete data were available. This is predictable given the degenerative nature of Alzheimer's Disease. All but 2 clients deteriorated and one-half of clients deteriorated 10 or more points on the Hierarchic Dementia Scale, indicating a change in functional abilities.
4. Family burden did not significantly increase for caregivers of clients maintained in the community, despite a significant increase in clients' severity of dementia.
5. Given clients' deterioration over program involvement, positive program outcome was defined as decrease or maintenance of family burden. In 2/3 of study cases burden was reduced or maintained. In six cases burden increased.
6. In 3 of the 6 cases in which burden increased, increase in burden could be attributed to extent of increase in dementia. Upon controlling for change in dementia, there were only 3 cases in which program effect was not evident.

B. Cost Comparison Analysis

The severity and progressive nature of Alzheimer's symptomatology has resulted in the most common health system response to Alzheimer's Disease being the institutionalization of the victim. While not denying the eventual need for institutional placement for most Alzheimer's individuals, the Day Away/Home Assistance Programs have adopted an innovative community care approach in an attempt to at least delay institutionalization.

An important question is whether the programs have been successful in delaying institutional placement of clients and, if this is the case, what have been the economic advantages in the way of cost savings to the health care system of this delay in placement?

Given the context in which this evaluation has been carried out, it is not possible to ascertain with certainty the number of program clients who would have been institutionalized. The evaluation used a one-group design. As we have indicated in the past, any conclusions about program effect in this case are somewhat tentative. In order to determine with certainty whether placement has been delayed, an equivalent comparison group and a sufficiently long follow-up period is required.

Even if it could be clearly demonstrated that the programs were successful in delaying institutional placement, in the context of the Ottawa-Carleton health care system, this would not likely mean a reduction in system costs. The growing demand for psycho-geriatric services in Ottawa-Carleton has resulted in long waiting lists for service and often placement waiting periods of between 12 and 18 months. With demand for institutional service exceeding capacity to this extent, a successful community program will perhaps reduce waiting periods. This will not translate into immediate cost savings to the system, but rather would mean a need for slower growth in the institutional sector, in terms of number of additional treatment spots required. If the programs can be shown to delay institutional placement and to provide

care at less cost, then it is a cost-effective method of providing new capacity.

Thus, the policy relevant question we have tried to answer is, "Have the programs delayed institutional placement and is this cost-effective when compared to institutional placement?"

Institutional placement was not used as a method of determining cost-effectiveness of the programs given the limitations of this study. First, Alzheimer's Disease is a degenerative condition for which we must often expect eventual institutional placement. In the absence of a comparison group it is not possible to determine if the 29% placement rate (n=13) over a six month period is high or low for this population. Indeed, with long waiting lists, this community program may well have been seen as a stop-gap measure for some of its clients. It should be acknowledged that some of these clients are recognized by referring health care workers and program staff alike to require institutional placement as soon as can be arranged.

Where clients come into the programs without being already on a waiting list for institutional placement, program activity will often result in placement on a waiting list. The programs provide for involvement with the Placement Coordination Service which identifies the most appropriate facility for the client and puts the client on record for future placement. Thus, placement on an institutional waiting list does not mean the programs were unsuccessful in an attempt to delay institutionalization, but rather reflects the programs' attempts to use an existing method of service coordination and to ensure the most appropriate placement is available when it becomes necessary.

Delay of institutional placement

Given the one-group design, the capacity of the health system in Ottawa-Carleton and the Programs' encouragement of clients to be placed on institutional waiting lists, a cost-effectiveness assessment must look at those clients for whom a judgement about delay in placement is possible.

Only six (21%) of the 29 clients still in the community were already on a waiting list for institutional placement prior to program admission. Only for these six clients can placement on a waiting list be seen as an indication of a decision to seek immediate institutional placement, for in these six cases, the placement on a waiting list was neither a spin-off of program activity nor a preparation for the eventual need for placement, but rather was the result of the caregiver's decision or willingness to accept institutional placement of the Alzheimer's individual.

Of these six individuals who entered the programs on institutional waiting lists and are still in the community, all six remain on waiting lists, none having been placed. Family caregivers for these six individuals were asked if they would now accept institutional placement if it were offered. Four indicated they would not accept placement if offered now, two indicated they would accept placement.

These results seem to indicate the programs have been successful in delaying institutionalization for some clients. This impression is strengthened when the comments made by these six family members are considered. While support provided by the programs was acknowledged by

the four relatives who would not now accept placement, this support was also acknowledged by the two family members who indicated they would accept placement if offered now.

In one case, the caregiver indicated a preference for continuing with community based care but expressed the fear that if placement were refused the Alzheimer's individual would lose his/her spot and return to the bottom of an 18 month waiting list. Continuation in the Day Away/Home Assistance Programs would have been preferred by the caregiver.

In the second case, recent deterioration in the Alzheimer's individual had resulted in an inability to participate in the Day Away Program. The caregiver indicated that had the Alzheimer's individual still been participating in the Day Away Program, institutional placement would have been refused.

Thus, in the absence of a controlled study, evidence of delayed institutional placement can be found for only the six individuals still in the community who had sought institutional placement prior to initial contact with the programs. For four of these six persons institutional placement would be refused if offered now, for one individual institutional placement would be refused if the opening could be held or guaranteed when required and for the remaining individual it appears institutional placement would have been refused as long as participation in the program was possible. Thus, of the total 44 clients in the study, a minimum of four delayed institutionalizations (9%) appeared to have occurred.

Program clients requiring institutional placement have been most often placed in one of four institutions: Beacon Hill Lodge, St. Jacques Nursing Home, Island Lodge and Elisabeth Bruyère Chronic Care Hospital. Beacon Hill Lodge and St. Jacques Nursing Home offer extended care in a nursing home setting. Island Lodge offers both extended and residential levels in a home for the aged, however, as most Alzheimer's admissions will be to the home's special care unit and will receive extended level care, the full per diem costs for this level have been reported. Elisabeth Bruyère provides chronic care in a hospital setting.

Current per diem rates in these institutions are as follows:

Beacon Hill Lodge	\$45.00
St. Jacques	\$45.00
Island Lodge	\$75.86
Elisabeth Bruyère Hospital	\$233.75

The Day Away Programs do not provide service to a client on a daily basis. Clients are served once each week. Thus, for comparison purposes, the monthly cost of maintaining a client in this community program will be compared to the monthly cost of institutional placement.

Mean monthly rates of institutional placement are as follows:*

Beacon Hill	\$1,368/month
St. Jacques	\$1,368/month
Island Lodge	\$2,306/month
Elisabeth Bruyère Hospital	\$7,106/month

* per diem rate times 30.4 days

Mean monthly costs of the Day Away Program have been calculated. These include payments by government in support of documented expenditure and certain operating expenses covered by the Alzheimer Society and client contributions such as client meals and secretarial assistance. Capital costs have not been included in the calculation.

Operating costs for the Day Away Program average \$10,495 per month. Clients attend one of three sessions each week. Numbers of clients at each Day Away session vary, however, a mean of 24.5 discrete clients participate each week. Thus, the monthly cost of maintaining a single client in the Day Away Program averages \$428.37/client/month.

Mean costs of the Home Assistance Program have been calculated. These are based on all operating expenses during the first and second quarters of fiscal year 1985-86. Total operating costs for the first six months of the 1985-86 fiscal year were \$29,584.56.

Client needs for the Home Assistance Program vary and, consequently, number of home visits per client vary. During the first and second quarters of fiscal year 1985-86 a total of 145 discrete clients were served by the Home Assistance Program. Thus, the mean cost of serving a single client in the Home Assistance Program was \$204.03 per client.

If we assume clients successfully maintained in the Day Away/Home Assistance Programs will require the services of both components, costs will average as follows:

$\$204.03, \text{ Home Assistance} + \$428.37 \times \text{number of months in Day Away Program}$

A six month service period, for example, would include \$204.03 for Home Assistance plus six months at \$428.37 for Day Away, giving a total six month cost for one client of \$2,774.

While total costs of institutional care at standard ward rates have been included, this is not the case for community care where indirect costs have not been considered. It must be recognized that the above costs of \$204.03 and \$428.37 per month do not represent the full cost of maintaining the Alzheimer's individual at home. Some families will carry additional burden while caring for the Alzheimer's individual, such as private nursing services. Other indirect costs not included in the calculation included those carried by the health care system, such as Chronic Home Care services.

VI. Survey of Other Alzheimer Day Programs

An extensive literature review and survey were conducted to gather information on other programs throughout Canada and the United States which provide respite, home assistance and day care services for Alzheimer's Disease individuals. A review of the literature revealed only two appropriate programs. A central list of services and programs could not be located either in Canada or the United States. To identify and locate programs, evaluators contacted Alzheimer's Society members throughout North America. Most of these members were unaware of the nature and location of these types of programs, but were able to provide other contacts who might have relevant information. Through this networking approach, evaluators were able to obtain the names and addresses of eighteen programs. For a complete list of programs and key contact persons see Appendix E. Questionnaires requesting information on program history, client characteristics, programs and services, administration, staffing, funding sources and problems in service delivery, were dispatched to all identified programs.

Information was received from 12 programs (67%). Five questionnaires were received from U.S. programs in California, Pennsylvania, New York and Massachusetts, and seven were Canadian, located in Ontario, Quebec, and Saskatchewan.

Program Objectives

All twelve programs surveyed provided day programs for Alzheimer's Disease individuals. Respondents expressed similar program objectives. For clients, objectives related to maintaining the individual at the highest possible functioning level, maintaining clients' self-esteem and independence, providing increased opportunities for socialization and stimulation in a safe environment and keeping clients in the community as long as possible.

The main objective for most programs in relation to caregivers was to provide respite. Secondly, programs endeavoured to give family support and to assist in managing clients' behaviour problems and health monitoring.

Program Histories

As with program objectives there was a great deal of similarity in factors surrounding program initiation. Respondents cited increased awareness among caregivers, professionals and the community as a whole, of the special needs of those with dementia, in particular Alzheimer's Disease. Existing programs for the elderly in many cases were found to be inappropriate for demented clients. Thus, specialized programs arose out of existing programs as the number of demented clients increased or new programs were established to meet growing needs.

Client Characteristics

There were no programs surveyed which served Alzheimer's Disease clients exclusively. Table 17 shows that one-half of the programs

served clients with Alzheimer's Disease and other related disorders only, while the other half in addition to serving Alzheimer's and other dementia clients, extended their services to those with other disabilities and/or to the general geriatric population.

Table 17 Client Characteristics: Population Served by Programs

Number of Programs	Population Served
6	Alzheimer's Disease and other related dementia disorders
2	Alzheimer's Disease, other dementia disorders, and the general geriatric population
1	Alzheimer's Disease, other dementia disorders, and those with physical disabilities due to neurological disease, psychiatric disorders and cardiac problems
1	Alzheimer's Disease, other dementia disorders and the mentally alert physically frail
1	general geriatric population
1	general geriatric population, the handicapped and chronically ill and under-privileged

Table 18 presents client characteristics for those clients who were reported to have Alzheimer's Disease. Nine programs (75%) indicated that over 50% of their clients had Alzheimer's Disease. Six programs served clients who were considered to be in the early and middle stages

Table 18 Client Characteristics: Alzheimer's Disease Clients

Percentage of Clients with Alzheimer's Disease	Number of Programs
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75 - 99%	2
50 - 74%	7
25 - 49%	2
less than 25%	1

Stages of Disease at which Clients Functioning	Number of Programs
---	--------------------

early and middle	6
middle	3
middle and late	3

Percentage of Clients with with Physical Impairment	Number of Programs
--	--------------------

over 50%	3
26 - 50%	3
5 - 25%	5
less than 5%	1

of the disease and six programs served those in the middle or middle and late stages. Six programs indicated that over 25% of their Alzheimer's Disease clients exhibited physical impairment as well as cognitive impairment, with these programs reporting over 50% with some physical impairment.

Respondents were asked to provide the average age of their clients and the age range. A mean taken of the average ages given by the twelve programs was 74 years. The largest age range indicated by a program was 40 to 99 years.

To summarize, most programs indicated that over 50% of their clients had Alzheimer's Disease. Half of the programs reported these clients were in the early and middle stages of the disease and half the programs indicated that 25% of these clients or more had physical impairment as well as cognitive impairment. There was no apparent relationship between stage of the disease and percentage of clients with physical impairment.

Program Operation

1. Admission Criteria

The programs surveyed were requested to indicate their program admission criteria. Programs cited admission criteria in the following categories:

medical requirements: diagnosis of Alzheimer's Disease or related dementia disorder; referral by a physician; medical examination within the last three months; absence of communicable disease.

self-care abilities: ability to self-feed, ability to self-toilet; manageable incontinence; absence of wandering behaviour; does not require one-to-one care; able to use program transportation or

provide alternative; ability to familiarize self with immediate surroundings.

social/behavioral/cognitive functioning: client must not exhibit any abusive or violent behaviour to self, staff or other clients; have need for social contacts; have some capacity for social interaction; show respect for property and safety of others; must not be excessively anxious.

other: client must be living at home or in setting other than a long-term care facility; age requirement of 60 years or older; caregiver must be willing to get involved with program; regular attendance required; demonstrated need for caregiver respite and care for client.

Nine programs had admission requirements in more than one of the above mentioned areas. One program indicated only a medical requirement for admission and one program based admission only on caregiver/client need for service. In one case, no admission criteria of any kind were reported.

2. Hours of Service

Table 19 presents frequency and duration of service with number of clients served. The majority of programs (58%) offer services five days a week. In most programs (75%) clients could attend every day that services were offered. The mean number of clients served per day was 14 with a range of 6 to 32. Only two programs provided full day care, i.e. between 8 and 10 hrs. daily. Seven programs provided service between five and six hours a day and three provided four hours or less per day. Most programs which provided five day per week service allowed clients to attend each day, and all offered at least five hours of service per day. Of the five programs which operated two or three days a week, all

Table 19 Description of Programs' Frequency, Duration and Number of Clients Served

Programs	Days service per week	Number individual clients/week	Number Served per day	Number of days/week client may attend	Hours of attendance time	# hrs./ day
A	5	51	32	up to 5	7 a.m. - 5 p.m.	10
B	5	100	30	2.5	9 a.m. - 4 p.m.	6
C	5	50	15 - 22	2	10 a.m. - 3 p.m.	5.5
D	5	70	15	2 to 5	9:15 a.m.- 3:30 p.m.	6.25
E	5	33	15 - 18	1 to 5	9 a.m. - 2 p.m.	5
F	5	30	14	1 to 5	9 a.m. - 5 p.m.	8
G	5	35	15 - 18	3 to 5	9 a.m. - 3 p.m.	6
H	3	36	8 - 12	1 to 2	10 a.m. - 3 p.m.	5
I	2.5	12	8 - 12	2.5	1:15 p.m. - 4 p.m.	2.75
J	2	6	6	2	10 a.m. - 2 p.m.	4
K	2	15 - 25	20	2	10 a.m. - 12:30 p.m.	2.5
L	2	8 - 10	7	1 to 2	10 a.m. - 3 p.m.	5

but one allowed client participation each day, and all operated five or less hours per day. A comparison of number of clients served per day with the number of individuals served each week revealed that most programs (75%) do not serve the same clients each day. Some clients choose or are permitted to attend only on some days of program operation, while others may attend each day. This rotation of clients accounts for the difference between number served per day and number of individuals served per week.

3. Transportation

Seven programs offered transportation service for clients: two programs were able to access community agency transportation services for clients and three used private transportation services either on contract or a fee-for-service basis. One program provided volunteer drivers and one provided service only on an emergency basis. Table 20 shows cost per client varied greatly from program to program. Only two programs offered free service for all their clients who required transportation. Five programs cited problems with cost and availability of transportation for clients.

4. Fee-for-Service

Nine programs (75%) reported that clients were required to pay fees. Table 21 presents per diem costs per client. As programs vary on the number of hours of service provided each day, cost has also been presented on an hourly basis. Cost for service ranged from 44 cents to

Table 20 Transportation Provided to Clients

Provided direct from program	Accessed through other community services	Type of service	Clients requiring service n (%)	Cost per client
	A	bus	40 (78)	\$.30/trip
B		car (emergency only)	2 (2)	—
C		bus	45 (90)	\$15-45/month*
	E	bus	15 (45)	none
G		taxi/chair car	35 (100)	\$8/\$36/trip*
H		taxi	29 (81)	\$8 round trip
I		car	5 (42)	none

* Subsidy available

Table 21 Client Fees-for-Service

<u>Program</u>	<u>Per diem rate</u>	<u>hourly rate</u>
A	\$30	\$3.00
B	\$23	\$3.80
C	none	—
D	\$14 - 70	\$2.24 - 11.20
E	\$10	\$2.00
F	\$5.25	\$.66
G	\$32 - 35	\$5.33 - 5.83
H	\$5	\$1.00
I	none	—
J	\$1.75	\$.44
K	none	—
L	\$12	\$2.40

\$11.20 per hour. Three programs charged a dollar or less per hour for service and four were in the two to four dollar per hour range. Two programs charged five dollars or more. Ten programs indicated that they provided lunch as part of the service. All programs which charged fees provided lunch to clients.

5. Physical Setting

Locations and facilities of programs ranged from shopping centre storefront operations to full-scale renovated facilities with a multitude of amenities and services. Following is a list of descriptions of physical settings provided by respondents.

Program

- A One large "all-purpose" room surrounded by sixteen rooms, which include: mechanical workshop; beauty shop; showers; washrooms; therapy room; nap room; nurse's station; offices; T.V. room; craft room; kitchen; storage. Special features: showers designed for clients in wheelchairs; therapy room equipped with whirlpool, weights, exercise equipment.
- B Located in a harbour area with 7,500 sq. ft. secured outdoor area and 3,600 sq. ft. indoor area consisting of four rooms.
- C Located in a hospital setting. The basement (garden level) has been renovated, Floor plan includes: large cafe-style dining room; kitchen/activities of daily living room; sick bay; staff meeting room; four offices; sound-proof workshop; large divided activity room; planting area.
- D Located in outpatient department in a rehabilitation hospital. Six multi-purpose rooms and three staff offices. Special features: solarium and orientation items throughout rooms, e.g. large clocks, signs, blackboards.
- E Located on ground floor with good wheelchair access and ample parking. Facility consists of two large group rooms; two large offices; large kitchen with direct access to a private park.

- F Located in an elementary school. A 6,000 sq. foot area renovated to provide service. Facility consists of four rooms for activities, crafts and dining, a large kitchen, small gymnasium; large patio and fenced grass area. Special features: alarm system and baking classes.
- G One open, bright, uncluttered main room; separate offices for nursing/social services. Special features: soft-form puzzles; low-frustration arts and crafts; moveable partitions.
- H Located in the basement of a large shopping area in a storefront. Floorplan includes a lounge, kitchenette, office, activity room and storage.
- I Located in an old house with surrounding grounds by a lake. One airy, bright room and long veranda and another room for recreation.
- J One large recreation room with work benches and various arts and crafts equipment available.
- K Located in a convent. Includes kitchen and recreation area. Special features: tape machine, piano and other musical instruments.
- L Located in a community centre. Facility consists of an airy room overlooking a children's play area; office; workrooms; halls with handrails. Special features: aquarium, plants.

Program Services

Services which day programs might offer to clients/caregivers were listed in pre-coded categories. Respondents were requested to indicate which services they provided to clients enrolled in day programs and which services were provided to caregivers.

1. Services to clients

Table 22 indicates that ten programs provided assessment services for their clients. Nine programs provided health care such as medication monitoring and health monitoring. One program offered a

dentist, ear and eye specialists, lab technician, physiotherapist and podiatrist as part of the service to clients.

All programs provided some type of activity programming. All offered recreational activities and cognitive exercises, e.g. orientation, memory games. Behaviour management techniques were used with clients in nine programs and most programs offered supportive counselling and made referrals for clients to other community services.

Table 22 Program Services Provided to Clients

Services Provided	No. of Programs (n=12)
Assessment	10
Health care	9
Activity Programming	
recreational	12
activities of daily living	10
mobility	9
cognitive exercise	12
Behaviour management techniques	9
Supportive counselling	10
Referral to other community services	11

2. Services to caregivers

One program did not indicate any services specifically for caregivers; this is primarily a recreational program wherein the spouse/caregiver attends with the client. Table 23 shows that all other programs provided respite for the caregivers. Most programs offered health counselling on clients' health status and education

concerning Alzheimer's Disease, other available community resources, and legal and financial matters. Counselling, referral to other community services and family support groups were other commonly provided services to caregivers. All but one program constructed individual plans for clients/caregivers to help them deal with specific problems.

Table 23 Program Services Provided to Caregivers

Services Provided	No. of Programs (n=12)
Respite	11
Health counselling re: client's health	10
Teaching behaviour management techniques	6
Education re:	
- Alzheimer's Disease	9
- Other available community resources	11
- legal and financial matters	8
Counselling	9
Referral to other community services	9
Family Support Groups	8

3. In-home services

In addition to the program services described above, eight programs (67%) indicated that they made home visits to their clients. In one case, this was only for initial client assessment. Only two programs reported providing in-home respite for clients not enrolled in the program. In both cases, volunteers provided the respite care.

4. Services to the Community

Respondents indicated services they provided to the community. Most programs provided in-service presentations or workshops, information to the general public on Alzheimer's Disease, and accepted student field placements. The majority of programs also trained professionals in the management of persons with Alzheimer's Disease.

5. Use of other services

To gauge the degree to which programs worked with other community services to provide comprehensive service to their clients, respondents were asked to name the community resources they frequently used. It appeared that all programs made extensive use of other agencies, institutions and support services in their communities. Services most frequently cited were medical, chiefly for client assessments, and caregiver home support and respite care.

Program Administration

Programs were administered either through volunteer societies such as the Alzheimer's Society and/or other community service agencies or through government agencies. Three programs reported they were freestanding.

1. Staffing

Information provided on program services demonstrated that most programs' services extended their mandate well beyond simple respite or custodial care. Programs surveyed delivered a variety of activities aimed at maintaining clients' functioning level at the highest level possible. An examination of types of staff positions and professional qualifications required for these positions reaffirmed the therapeutic approach of the programs. Programs had various titles for the positions staff had. Appendix E contains a complete list of staff titles, related qualifications and weekly hours worked for each program. Professional staff fell into four broad categories: directors/co-ordinators; therapists and aides; social workers; medical staff -- physicians, registered nurses. Virtually all staff members in these categories held university or college degrees in specialties related to their positions. Directors presented with a variety of professional backgrounds including psychology, nursing and gerontology. There were a variety of therapists and aides among program staff, e.g. recreation, art, dance, occupational.

To assess whether professional staff were used on a consultative basis or if they provided most of direct care to clients, data on the number of hours worked by each staff member were collected. Nineteen professional staff members (53%) were reported to work full time and nine professionals (25%) were reported to work half-time. It is apparent that most programs surveyed utilize professional staff for the majority of their service delivery.

Volunteers were used extensively by all programs surveyed. An examination of total volunteer hours per week and total program hours per week indicated that most programs used volunteers at least 50% of the time. Four programs used volunteers on a full-time basis and two programs provided all their home respite services through volunteers.

2. Funding Sources

Eight programs provided complete information on sources of funding. Five programs received the majority of their funding from public sources, i.e. government departments and funded agencies. Of the three programs which received the majority of their funding from private sources, two relied on client fees for approximately one-half of their revenue and the other was fully funded by a community service agency. Four programs indicated that their funding bases were not secure.

Program Impact and Future Plans

Respondents were asked to assess the effectiveness of their programs by indicating where they felt the program had had its greatest impact: in the community; with clients; with individual families; in institutional facilities; and/or in advocacy. Categories were not exclusive. All programs responded that their greatest impact had been with clients and individual families. Approximately 25% of respondents also felt their programs had had significant impact in the community, in institutions, and in an advocacy role.

Nine respondents indicated that changes were planned for their programs. Plans included developing volunteers in terms of specific job

descriptions and specialized training; beginning family support groups; feasibility assessment of a three-week respite program; expansion of hours of operation.

Comparison of Day Away/Home Assistance Programs with Surveyed Programs

There appeared to be a marked similarity between the Day Away/Home Assistance programs and the other programs surveyed. Although primarily day programs, most offered in-home service as well. A therapeutic rather than custodial approach to client care had been adopted, and service was provided to both the client and the caregiver. As with the Day Away/Home Assistance programs the majority of client care was delivered by professional staff, and trained volunteers played an important role in service delivery.

There were no programs surveyed which limited program admission to those with a confirmed Alzheimer's Disease diagnosis. One-half of programs accepted those with Alzheimer's Disease and other dementia disorders, and one-half accepted these as well as other members of the geriatric population. Respondents indicated, however, that programs had been initiated due to the need for specialized services for those suffering from dementia. Thus programs are designed for the needs of their demented clients, as opposed to general seniors' day programs which may accept some Alzheimer's clients. This is reflected in the proportion of Alzheimer's clients in the programs. Nine programs indicated that over 50% of their clients had an Alzheimer's diagnosis.

Day Away/Home Assistance clientele was unique in being exclusively Alzheimer's individuals. Other programs while focusing on Alzheimer's clients accepted a broader clientele.

Although the Day Away Program offered more hours of service per day than most other programs, it was unique in offering service to clients only one day per week. The majority of programs surveyed provided five day per week service and allowed clients to attend on each day of operation. Thus, the majority programs provided service more frequently than the Day Away Program.

Fee-for-service varied from program to program, with a range of \$.44 to \$11.20 per hour per client. Day Away was comparatively at the low end of the cost spectrum with a per client hourly fee of \$1.45.

Of the eight programs who supplied information on their funding sources, five received public funding, i.e. from government departments and funded agencies.

A comparison of the Day Away/Home Assistance programs with other programs has shown a basic similarity in approach and service delivery to clients and their caregivers. All programs were initiated to meet the special needs of the Alzheimer's individual. Other programs differed most notably from the Day Away Program in their inclusion of clients with other types of dementia and geriatric problems among their clientele.

Summary of Results

1. All programs were initiated as a response to increasing demand for services for victims of dementia.
2. All program objectives went beyond simple provision of respite care and addressed the therapeutic needs of clients and caregivers.
3. No program served Alzheimer's Disease individuals exclusively, but rather a mixture of those with other types of dementia and in some cases other groups within the geriatric population with related needs.
4. The majority of clients in most programs were diagnosed Alzheimer's Disease individuals.
5. Programs varied in frequency and duration of services offered. Days of service varied from 2 to 5 days per week and hours of service ranged from 2.5 per day to 10 per day, with the most typical hours of service being between 5 and 6 hrs. per day. Most programs allowed client participation on each day of operation.
6. The majority of programs charged between \$1 and \$4 per hour per client for service.
7. Most programs offered a full range of services to both clients and caregivers, including assessment, health care, activity programming, referrals, respite, health counselling and education in Alzheimer's Disease and related problems.
8. Programs tended to employ staff with professional backgrounds to deliver services. Nurses, psychologists and a variety of therapists e.g. recreational, occupational were listed among programs' staff.
9. Most programs received the majority of their funding through public sources.
10. Respondents felt that their programs' greatest impact was with clients and their families.
11. A comparison of the Day Away/Home Assistance Programs to surveyed programs revealed a great deal of similarity in terms of program objectives and types of services offered to clients and caregivers.

VII. CONCLUSIONS

The Société Alzheimer Society of Ottawa-Hull Day Away/Home Assistance Programs have in the past year developed and implemented a model of service for assisting Alzheimer's victims in the community and their family caregivers. With the support of the Ontario Ministries of Community and Social Services and Health, a volunteer program has developed into a funded, credible program providing services to Alzheimer's victims, caregivers, other professionals, and to the community at large.

Three key aspects of the Day Away/Home Assistance Programs are the integration of the programs into the treatment system, the provision of specialized assessment and management services and the provision of respite care.

The programs have been successful in establishing links with existing services in Ottawa-Carleton. The survey of agencies, as well as case records, indicate strong referral links between the programs and other agencies in the community. The programs have made excellent use of the Placement Coordination Service so as to increase the chances of timely institutional placement when it becomes necessary.

Agencies in Ottawa-Carleton have identified the need for specialized assessment of the demented as a serious gap in service. The agency survey clearly indicates satisfaction with the programs' role in specialized assessment.

The third key aspect of the programs is the provision of respite. This component was seen by caregivers and staff to be an essential

component of a community program. It should be noted that in a community such as Ottawa-Carleton, with a significant shortage of institutional places for Alzheimer's individuals, respite for family caregivers is of great importance.

It should be expected that clients receiving care will have their dementia worsen with time. For the clients of those programs there was a significant increase in dementia over the follow-up period. Despite the almost universal increase in dementia, burden experienced by caregivers increased for only one-third of the cases. For two-thirds of the caregivers, burden either was reduced or maintained at the same level. While direct causality cannot be inferred, it is not unreasonable to assume the program contributed to this result.

There was evidence in this study that for some clients the program delayed institutional placement. A controlled study would be required to assess the degree to which placement can be deferred.

Given the extremely high satisfaction expressed by caregivers, it appears this program may, for some clients, be an alternative to institutional placement until such time as their needs change. Providing home assistance and once per week respite care, it is also a cost-effective alternative to institutional care, at least for a certain time period.

It is important that the programs and the Ministries work to best match clients to the appropriate treatment location. In the immediate future the programs will likely continue to accept some patients requiring institutional placement for whom beds are not available.

Clients should, however, increasingly be placed in the care location which best meets their individual needs and those of the caregivers, either community care or institutional care.

While evidence was not collected in this regard, it is quite possible that the quality of care provided in a specialized community program can be significantly better than that provided in a non-specialized nursing home.

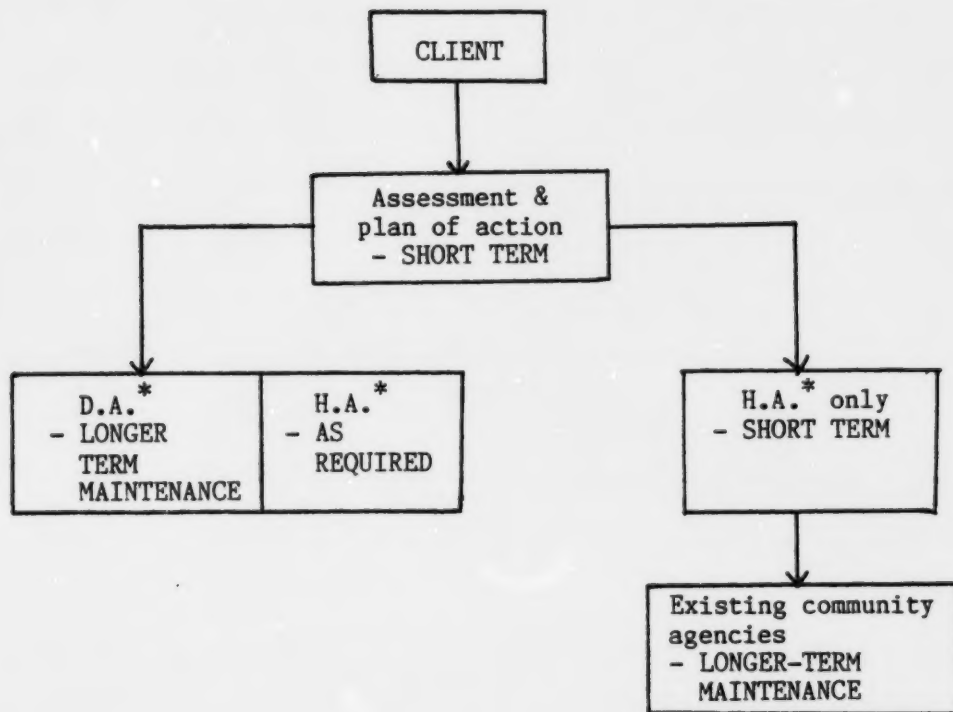
Issues To Be Considered

1. Model of Service and Staffing

Although the Day Away and Home Assistance Programs operate in tandem, there are some clear differences in program operation. Day Away clients and caregivers appear to receive different program components than do Home Assistance clients. Day Away clients received more therapeutic services than did Home Assistance clients. Home Assistance client activity was focused on activities related to assessment and agency contacts. Caregivers of clients in Home Assistance, however, received more contact than did caregivers of clients in Day Away.

Figure 3 outlines the flow-through of clients through the two programs. All clients initially receive home assessment under the auspices of the Home Assistance Program. Following the preparation of a plan of action, the client may become enrolled in Day Away or remain on Home Assistance only.

Assessment and service provided to Home Assistance only clients require, on the whole, short-term involvement of staff with clients and



* D.A. = Day Away

* H.A. = Home Assistance

Figure 3 Current Model of Service

caregivers. Case management is transferred to appropriate, community-based agencies, where possible, for longer term maintenance. The Day Away Program, however, provides the longer-term care required following assessment, with a home assistance component utilized as required.

The two programs are operating very differently. The Day Away Program is able to service a very limited number of clients, given that longer-term care is being provided. With the emphasis on assessment, development of a plan of action, and transfer to existing agencies, the Home Assistance only Program has a much greater client capacity in terms of discrete clients served. The Home Assistance only Program is focusing on acute involvement with clients and caregivers while the Day Away/Home Assistance Program is focusing on the provision of longer-term therapeutic care.

An alternative model of care was recommended by several staff members during personal interview. Figure 4 illustrates a two phase model of care, which in fact, parallels the model of service already being utilized by the Home Assistance only Program. Program staff recommended a program focused on acute, early involvement with clients and caregivers, followed by transfer of case management to existing services and/or satellite day programs. Thus, longer-term maintenance would be relinquished to other community agencies.

It appears this model would have several advantages. The highly trained team would be able to use their special skills more efficiently. Certain aspects of the program requiring less specialized staff could be performed elsewhere. The highest cost staff are already in place. Staff requirements for maintenance would allow use of lower paid staff

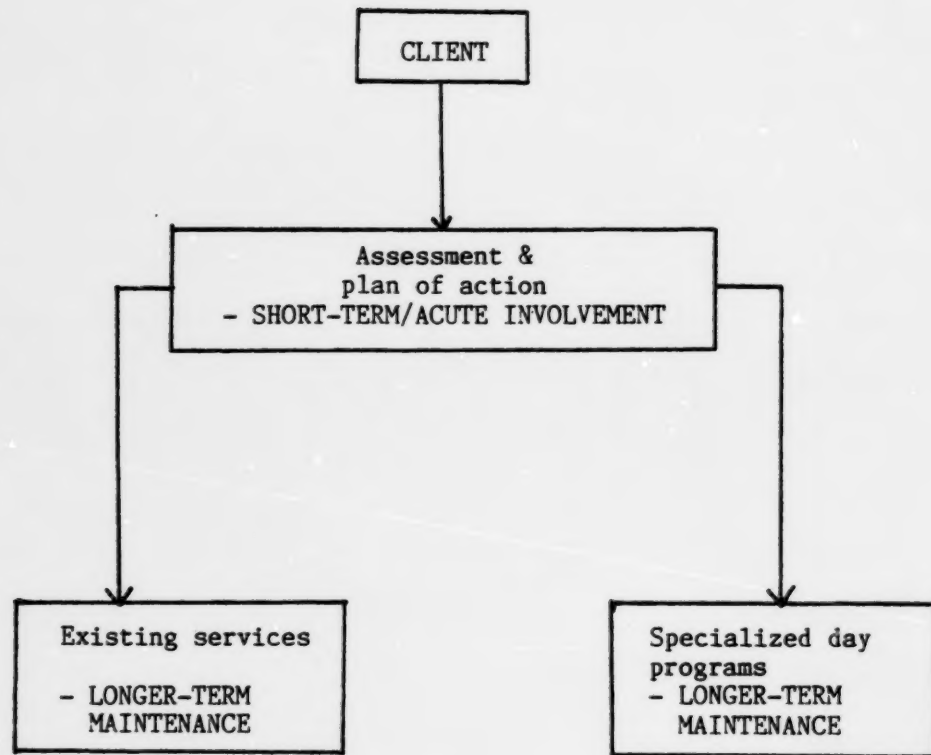


Figure 4 Proposed Model of Service

and volunteers. Capacity should increase with disproportionately lower incremental costs. Last, satellite day programs could operate over a wider geographic area.

2. Clientele

It is not evident that there is a programmatic reason to exclude dementing patients other than those with Alzheimer's Disease. The need recognized in the community for specialized assessment is being addressed by the programs. It may be a more efficient use of resources to extend eligibility for this service to all dementing individuals.

3. Large Centres vs. Smaller Centres

This program has taken extreme care to become well integrated into the service network. Other services available in the community are used extensively by this program. Given the fewer services available in a smaller centre, especially diagnostic and assessment services, the role of the program in terms of the amount of direct service required in comparison to a program located in a large centre should be considered.

Prior to determining the feasibility of establishing these programs elsewhere in the province, a number of questions need to be addressed; namely, which model of service is most suitable in terms of efficiency and effectiveness?; should clientele be expanded to include all dementing individuals?; and do large centres and smaller centres require somewhat different models of service?

APPENDIX A

DAP ()
HAP only ()
Being processed ()

Client Name _____

Major Activity Monitoring Sheet
CLIENT

Activity	1	2	3	4	5	6	7	8	9	10
1. assessment										
a. initial										
b. ongoing										
c. 6 mo. follow-up										
2. health care										
a. medication monitoring										
b. health monitoring										
c. health counselling										
3. activity programming										
a. recreational										
b. ADL										
c. communication										
d. mobility (gross motor)										
e. cognitive exercise										
4. behaviour management techniques										
5. supportive counselling										
6. agency referral/info. re client										
7. linkage with agencies										

8. Was client discharged this week?

() Yes () No Date _____

9. Number of home visits _____

NOTE: ON BACK PLEASE LIST AGENCIES TO WHOM
CLIENT HAS BEEN REFERRED

Client Name _____

Major Activity Monitoring Sheet

SIGNIFICANT OTHERS

Frequency of activity

	1	2	3	4	5	6	7	8	9	10
1 a										
1 b										
1 c										
1 d										
2 a										
2 b										
3										
4										
5										

1. education
a. health

b. available community resources

c. legal and financial matters

d. management techniques

2. counselling
a. supportive

b. directive

3. management programming

4. agency referral

5. ongoing assessment of caregiver's needs

6. caregiver diary/teaching sheet

() Yes () No

7. family support group (if known)

() Yes () No

8. No. of contacts prior to initial assessment _____

NOTE: ON BACK PLEASE LIST AGENCIES TO WHOM CAREGIVER HAS BEEN REFERRED

Major Activity Monitoring Sheet

COMMUNITY

Frequency of activities

	1	2	3	4	5	6	7	8	9	10
1										
2a										
2b										
3										
4										

1. liaison with community

2. in-service programs
a. presented

b. attended

3. student field placements

4. Family Support Groups

Staff
Initials

Date: _____

STAFF ACTIVITY TIME MONITORING

		Program Activities										Client/Caregiver Activities									
		Program development	Staff development	Case conferencing	Charting	Report writing	Caseload management	Travel	Housekeeping and activity preparation	Community liaison - general	Student field placements	Enquiries re: new clients	Client assessment	Face-to-face contact DAP	Face-to-face contact HAP	Community liaison-DAP re: client	Community liaison-HAP re: client	Telephone contacts	Family support group		
8	30																				
	45																				
	00																				
9	15																				
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10	15																				
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Date: _____

Program Activities

Program Activities		Client/Caregiver Activities
Administration		
Program Development		
Staff Development		
Staff Supervision		
Community Liaison - General		
Student Field Placements		
Case Conferencing		
Charting		
Report Writing		
Travel		
Enquiries re New Clients		
Telephone Contacts		
Face-to Face Contact		
Community Liaison - re Clients		
Family Support Groups		

TOTAL

APPENDIX B

Caregiver Interview Form

From case record:

1. Client/caregiver number _____
2. Age of client _____ Age of caregiver _____
3. Sex of client 1.() male 2.() female
Sex of caregiver 1.() male 2.() female
4. Relationship of caregiver to client
 - 1.() spouse
 - 2.() son/daughter(in-law)
 - 3.() sister/brother
 - 4.() other: specify _____
5. Date of initial assessment _____
6. Program
 - 1.() Day Away Date of first attendance _____
 - 2.() Home Assistance Program admission date _____
7. Hierarchical Dementia Scale
Intake score _____ Follow-up score _____
8. Family Burden Index
Intake score _____ Follow-up score _____
9. Length of stay in program: # weeks to date _____
Discharge date: _____
Discharged to: _____

From interview with caregiver:

1. Could you look over this list with me and tell me which of these services were provided to you and your (relative) by the Day Away/ Home Assistance Program. We will go over the list item by item. For each type of service provided, I will ask you to tell me how helpful it was to you. On the scale from 1 to 5, please rate the helpfulness of each service. A score of 1 means the service was not helpful at all, a score of 3 means it was somewhat helpful, and 5 means it was very helpful.
(Give list of services to the caregiver)

<u>Services</u>	<u>Used</u> Yes/No	<u>Helpfulness rating scale</u>				
		not at all helpful	somewhat helpful	very helpful		
a. Day Away Program Which day? _____	a. _____	a. 1	2	3	4	5
(If score 3 or above) What did you find helpful about the Day Away program?						
b. Transportation to Day away	b. _____	b. 1	2	3	4	5
c. Respite at home (Stay with your relative while you went out)	c. _____	c. 1	2	3	4	5
d. Information about Alzheimer's Disease	d. _____	d. 1	2	3	4	5
e. Information about other services avail- able in the community	e. _____	e. 1	2	3	4	5
f. Information about legal & financial matters	f. _____	f. 1	2	3	4	5
g. Counselling & support (someone to talk to about difficulties in caring for a person with A.D.)	g. _____	g. 1	2	3	4	5
h. Caregiver diary	h. _____	h. 1	2	3	4	5
i. Family support group	i. _____	i. 1	2	3	4	5
j. Services related to your (relative's) physical health	j. _____	j. 1	2	3	4	5

Techniques to help with specific problems:

The Program develops a plan to help with each client's specific problems. Did you receive help with any specific problems your (relative) may have had in the following areas?

<u>Services</u>	<u>Used</u> Yes/No	<u>Helpfulness Rating Scale</u>				
		not at all helpful	somewhat helpful	very helpful		
k. Recreational activities	k. ____	k. 1	2	3	4	5
l. Activities of daily living, eg; eating, dressing, toileting	l. ____	l. 1	2	3	4	5
m. Communicating	m. ____	m. 1	2	3	4	5
n. Exercise	n. ____	n. 1	2	3	4	5
o. Memory problems	o. ____	o. 1	2	3	4	5
p. Nutrition	p. ____	p. 1	2	3	4	5
q. Behaviour problems	q. ____	q. 1	2	3	4	5
r. Were there any other services you received from the Day Away/Home Assistance Program that I haven't mentioned?						

<u>Services</u>	<u>Helpfulness Rating Scale</u>				
-	1	2	3	4	5
-	1	2	3	4	5
-	1	2	3	4	5

2. Were you referred by the Program to any other services? How helpful were these services to you?

<u>Services</u>	<u>Helpfulness Rating Scale</u>				
-	1	2	3	4	5
-	1	2	3	4	5
-	1	2	3	4	5

3. Did the Program actually provide what you expected it to?

- 1. () Yes
- 2. () No
- 3. () Uncertain

Comments:

4. Could you tell me if you experienced any problems in the following areas:

	Yes	No
a. length of time from your first contact with the program to actually being admitted or receiving service.	()	()
b. availability of staff	()	()
c. hours of service	()	()
d. cost	()	()
e. transportation (if Day Away)	()	()
f. any other problems?	()	()

5.

5. Do you have any suggestions that could help improve the Program?

6. On the whole, how satisfied have you been with the Program?

1
not very
satisfied

2

3
somewhat
satisfied

4

5
very
satisfied

(IF CLIENT IN FACILITY CARE, GO TO QUESTION 13)

7. Was your (relative) on a waiting list for placement in a facility before you contacted this Program?
(If no, go to next question)

() Yes () No

Is she/he still on a waiting list? () Yes () No

(If yes)

If you were offered placement now, would you accept it?

() Yes () No

(If no)

Did you take your (relative) off the waiting list because of the help you received from the Program?

() Yes () No

8. Apart from the Program, what professional services are you now receiving? (eg., nursing care, homemaking services)

<u>Agency/Service Provider</u>	<u>How Often</u>	<u>Is this enough?</u> <u>Yes/No</u>	<u>(If no,)</u> <u>How Often</u>
--------------------------------	------------------	---	-------------------------------------

9. Are there other family members, neighbours or friends who help out?

Relationship

How Often

10. Are you receiving enough help from professional services and family/friends to enable you to care for your (relative) at home?

() Yes () No

(If no) How much more help do you feel you need?

Agency/Service Provider

How Often

11. Have you been turned down for any services you have requested?

() Yes () No

(If yes) What were these services ? Why were you denied service?

12. Has taking care of your (relative) become more difficult, less difficult, or about the same over the last 6 months?

- ☐ More difficult
- ☐ Less difficult
- ☐ No change

(If more difficult)

Why has taking care of your (relative) become more difficult?
Is it because the Alzheimer's Disease has progressed over the last 6 months?

Have any changes in your family life occurred that have made it more difficult? eg., loss of respite or support person, illness or death in the family, unemployment, other family crisis?

(If less difficult)

Has the Program made it less difficult for you?

Have there been any changes in your family life that have made it less difficult for you? eg., additional sitters, recovery from illness, involvement with other agencies/services

13. Do you have any other comments about the Program and how it could help people who are caring for persons with Alzheimer's Disease in their home?

APPENDIX C

Agency Survey

1. Please describe the working relationship of your agency to the Société Alzheimer Society Day Away/Home Assistance Program:
 - a. () our agency refers clients to the Day Away/Home Assistance Program.
 - b. () the Day Away/Home Assistance Program refers clients to our agency.
 - c. () both of the above.
2. Have you experienced any problems in referring to or receiving referrals from the Day Away/Home Assistance Program?

Please respond to Question 3 if you refer to the Day Away/Home Assistance Program.

3. a. Prior to the existence of the Day Away/Home Assistance Program, what referrals or arrangements were made by your agency for clients with Alzheimer's Disease? Please comment on your satisfaction with these referrals or arrangements as compared with the Day Away/Home Assistance Program.

- b. Do you currently refer your clients with Alzheimer's Disease to any other services apart from the Day Away/Home Assistance Program? If yes, please specify.

Please respond to Question 4 if you receive referrals from the Day Away/Home Assistance Program.

4. What services do you provide to clients referred from the Day Away/Home Assistance Program?

5. Would you rate provision of service at the Day Away/Home Assistance Program as:

1 2 3 4 5
unsatisfactory satisfactory excellent

6. Do you have any suggestions as to how the Day Away/Home Assistance Program could improve its service?

7. Do you feel there is a need for a therapeutic day care and home assistance program which serves Alzheimer Disease clients exclusively in Ottawa-Hull?

1	2	3	4	5
very little need		moderate need		high need

8. Do you feel the designation of a separate program to provide day care and home assistance for Alzheimer's individuals and their caregivers represents an overlap of service?

1	2	3	4	5
very little overlap		some overlap		extensive overlap

9. Any other comments?

Thank you for your cooperation.

APPENDIX D

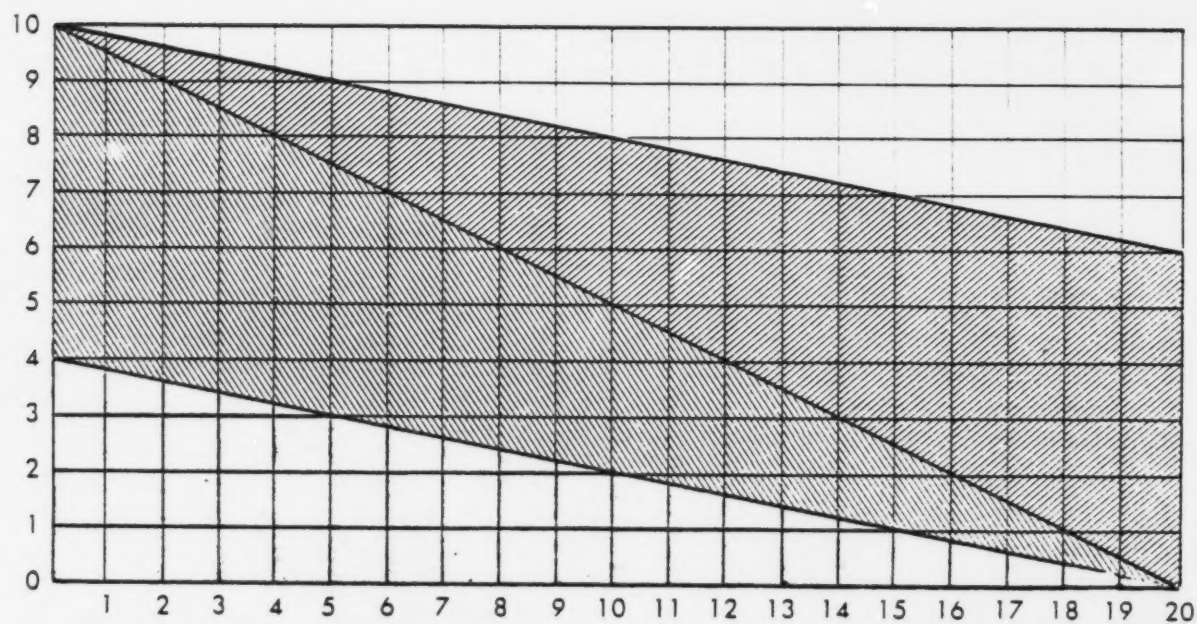
HIERARCHIC DEMENTIA SCALE (Cole and Dastoor)

Identification _____

Examiner _____

Date of Exam _____

Score _____



Minimal
Mild
Moderate
Severe



1. Orienting

10. No impairment
8. Shakes Examiner's Hand
6. Reacts to Auditory Threat
4. Reacts to Visual Threat
2. Reacts to Tactile Threat

2. Prefrontal

10. None
8. Tactile Prehension
6. Cephalobuccal Reflex
4. Orovisual Reflex
2. Oral Tactile Reflex

3. Ideomotor

10. Reversed Hands
9. Double Rings
8. Double Fingers
7. Opposed Hands
6. Single Ring
5. Single Finger
4. Clap Hands
3. Wave
2. Raise Hands
1. Open Mouth

4. Looking

10. Finds Images
8. Searches for Images
6. Grasps content of Picture
4. Scans Picture
2. Looks at Picture

5. Ideational

10. Imaginary Match and Candle
9. Imaginary Nail and Hammer
8. Imaginary Scissors
7. Imaginary Comb
6. Match and Candle
5. Nail and Hammer
4. Scissors
3. Comb
2. Put on Shoes
1. Open Door

6. Denomination

10. No Errors
9. Nominal Aphasia — Parts
8. Nominal Aphasia — Objects
7. Use of Parts
6. Use of Objects
5. Conceptual Field — Parts
4. Conceptual Field — Objects
3. Sound Alike — Parts
2. Sound Alike — Objects
1. Deformed Words

7. Comprehension

Verbal:

5. Close eyes and touch left ear
4. Clap hands three times
3. Touch your right eye
2. Touch your nose
1. Open mouth

Written:

5. Close eyes and touch left ear
4. Clap hands three times
3. Touch your right eye
2. Touch your nose
1. Open mouth

8. Registration

10. Spoon, candle, scissors, button, whistle
8. Spoon, candle, scissors, button
6. Spoon, candle, scissors
4. Spoon, candle
2. Spoon

9. Gnosis

10. Superimposed Words
9. Superimposed Images
8. Digital Gnosis
7. Right-Left — Examiner
6. Right-Left — Self
5. Body Parts — Examiner
4. Body Parts — Self
3. Touch (pinch) 5 cm
2. Touch (pinch) 5 — 15 cm
1. Response to Touch (pinch)

10. Reading

10. Paragraph
8. Paragraph with error (s)
6. The cat drinks milk.
4. Receive
2. M

11. Orientation

10. Date
8. Month
6. Year of Birth
4. Morning or Afternoon
2. First Name

12. Construction

10. Four Blocks Diagonal
8. Four Blocks Square
6. Two Blocks Diagonal
4. Two Blocks Square
2. Form Board Circle

13. Concentration

10. Serial 7's (100, 93, ...)
9. Serial 3's (30, 27, ...)
8. Months of Year Backwards
7. Days of Week Backwards
6. 93 - 85
5. 10 - 1
4. Months of Year Forwards
3. Days of Week Forwards
2. 1 - 10
1. Actual Counting

14. Calculation

10. $43 - 17$
9. $56 + 19$
8. $39 - 14$
7. $21 + 11$
6. $15 - 6$
5. $18 + 9$
4. $9 - 4$
3. $8 + 7$
2. $2 - 1$
1. $3 + 1$

15. Drawing

10. Cube
9. Cube (difficulty with perspective)
8. Two Rectangles
7. Circle and Square
6. Rectangle
5. Square
4. Circle Inside Circle
3. Circle
2. Line
1. Scribble

16. Motor

10. No Impairment
9. Increased Muscle Tone — Repeated
8. Increased Muscle Tone — Initial
7. Loss of Rhythm
6. Loss of Associated Movements
5. Contractures of Legs
4. Kyphosis
3. Vertical Restriction of Eye Movement
2. Non-ambulatory
1. Lateral Restriction of Eye Movement

17. Remote Memory

10. Amount of pension
8. Number of grandchildren
6. Year of marriage or of first job
4. Father's Occupation
2. Place of Birth

18. Writing**Form:**

5. Flowing Style
4. Loss of Flow
3. Letters Misshappen
2. Repetition or Substitution of Letters
1. Scribble

Content:

5. No Error
4. Word Substitution
3. Missing Preposition
2. Missing Verb or Noun
1. Missing 3 or 4 Words

19. Similarities

10. Airplane — Bicycle
8. Gun — Knife
6. Cat — Pig
4. Pants — Dress
2. Orange — Banana

20. Recent Memory

10. All Five
8. Any Four
6. Any Three
4. Any Two
2. Any One

Family Burden Index
BURDEN INTERVIEW

INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way, never, rarely, sometimes, frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?
0. never 1. rarely 2. sometimes 3. frequently 4. nearly always
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?
0. never 1. rarely 2. sometimes 3. frequently 4. nearly always
3. Do you feel stressed between caring for you relative and trying to meet other responsibilities for your family or work?
0. never 1. rarely 2. sometimes 3. frequently 4. nearly always
4. Do you feel angry when you are around your relative?
0. never 1. rarely 2. sometimes 3. frequently 4. nearly always
5. Do you feel that you[✓]relative currently affects your relationship with other family members or friends in a negative way?
0. never 1. rarely 2. sometimes 3. frequently 4. nearly always
6. Do you feel embarrassed over your relative's behavior?
0. never 1. rarely 2. sometimes 3. frequently 4. nearly always
7. Are you afraid what the future holds for your relative?
0. never 1. rarely 2. sometimes 3. frequently 4. nearly always
8. Do you feel your relative is dependent upon you?
0. never 1. rarely 3. sometimes 3. frequently 4. nearly always
9. Do you feel strained when you are around your relative?
0. never 1. rarely 3. sometimes 3. frequently 4. nearly always
10. Do you feel your health has suffered because of your involvement with your relative?
0. never 1. rarely 3. sometimes 4. frequently 5. nearly always

11. Do you feel that you don't have as much privacy as you would like, because of your relative?
0. never 1. rarely 3. sometimes 4. frequently 5. nearly always
12. Do you feel that your social life has suffered because you are caring for your relative?
0. never 1. rarely 3. sometimes 4. frequently 5. nearly always
13. Do you feel uncomfortable about having friends over, because of your relative?
0. never 1. rarely 3. sometimes 4. frequently 5. nearly always
14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?
0. never 1. rarely 3. sometimes 4. frequently 5. nearly always
15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?
0. never 1. rarely 3. sometimes 4. frequently 5. nearly always
16. Do you feel that you will be unable to take care of your relative much longer?
0. never 1. rarely 3. sometimes 4. frequently 5. nearly always
17. Do you feel you have lost control of your life since your relative's illness?
0. never 1. rarely 3. sometimes 4. frequently 5. nearly always
18. Do you wish you could just leave the care of your relative to someone else?
0. never 1. rarely 3. sometimes 4. frequently 5. nearly always
19. Do you feel uncertain about what to do about your relative?
0. never 1. rarely 3. sometimes 4. frequently 5. nearly always
20. Do you feel you should be doing more for your relative?
0. never 1. rarely 3. sometimes 4. frequently 5. nearly always
21. Do you feel you could do a better job in caring for your relative?
0. never 1. rarely 3. sometimes 4. frequently 5. nearly always
22. Overall, how burdened do you feel in caring for your relative?
0. never 1. rarely 3. sometimes 4. frequently 5. nearly always

APPENDIX E

We are conducting a survey of programs for Alzheimer's individuals in Canada and the U.S.A. for the Ministry of Community and Social Services. This survey is an important component of an evaluation of the Société Alzheimer Society of Ottawa-Hull Day Away/Home Assistance Programs.

We are attempting to locate other programs who provide a day program or a home assistance program (excluding respite only programs) in order to learn what others are doing in other communities. This information will be used by the Alzheimer Society and program staff to improve their program and by the Ministry of Community and Social Services in program development and policy decision-making.

The enclosed questionnaire requests information on your program. It is structured to reduce the time required by you to complete the questionnaire. Most items simply require a ✓ to indicate appropriate categories. Please complete the questionnaire and return to us by November 25 in the enclosed self-addressed envelope. Any pamphlets or additional information on your program would also be appreciated.

As you may appreciate, programs specifically for Alzheimer's individuals are rare. A central registry of these programs has not been prepared. It appears that programs are operating in isolation in the development of service models to provide care for Alzheimer's Disease individuals. If sufficient programs are interested, we will prepare and send you a copy of summarized results of our survey and names and addresses of programs participating in the survey. Please indicate below if you would be interested in receiving this material.

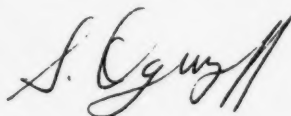
We realize that program staff are extremely busy and pressed

-2-

for time. Given the sparsity of these programs, your contribution to this survey is very important. We regret not being able to provide you with more time to complete the questionnaire; however, tracking of programs took much longer than anticipated.

Thank you for your cooperation.

Yours truly,



S. Ogurzssoff
Consultant and Partner

sl

enclosure

I do _____ do not _____ consent to include our program information in an information package to be shared with other programs.

I am _____ am not _____ interested in receiving this information package.

Signed: _____

Organization: _____

Survey of Programs for Clients with Alzheimer's Disease

Client Characteristics and
Program History

1. Do you provide service to:
 1. ☐ clients with Alzheimer's Disease ONLY
 2. ☐ clients with Alzheimer's Disease and other dementia disorders
 3. ☐ the general geriatric population requiring your services
 4. ☐ other; please specify _____
2. Could you estimate the percentage of your clientele who have been diagnosed as having Alzheimer's Disease?
 1. ☐ 100%
 2. ☐ 75 - 99%
 3. ☐ 50 - 74%
 4. ☐ 25 - 49%
 5. ☐ less than 25%
3. At which stages of the disease would your clients typically be functioning? (you may check more than one)
 1. ☐ early stages
 2. ☐ middle stages
 3. ☐ late stages
4. Apart from cognitive impairment, what per cent of your clients with Alzheimer's Disease also exhibit physical impairment?
 1. ☐ over 50%
 2. ☐ 26 - 50%
 3. ☐ 5 - 25%
 4. ☐ less than 5%
5. What is the average age and age range of your clients?

Average age _____ Range _____
6. Have you always provided service to persons with Alzheimer's Disease?

☐ Yes ☐ No



Please relate the process that led to the introduction of Alzheimer's individuals into your program. (If more space is required, continue on next page)

7. If your program serves Alzheimer's individuals exclusively, please relate how and why the program was established.

Programs and Services

A. Day Care Programs

1. Do you offer a day program for Alzheimer's individuals?

() Yes

() No → go to page 7
Other Programs and
Services

2. How many days per week is the day program offered? _____ days

3. How many clients are served per day? _____ clients

4. How many days per week would a client attend the day program? _____ days

5. What are the hours that a client would attend the day program?

_____ a.m. to _____ a.m./p.m.

6. How many individual clients would attend the day program over a one week period? _____ clients

7. Do you have a waiting list?

() Yes

() No



How many persons are currently on the waiting list? _____ persons

8. Do you provide transportation for some/all clients?

() Yes

() No



What type of transportation is provided?

How many clients per week would require transportation? _____ clients

Do clients pay for transportation service?

() Yes

() No

What is the transportation cost per client trip? \$ _____

9. Is lunch provided?

() Yes

() No

10. Please indicate how long your day program has been operating.

11. Do clients pay a fee to attend the day program?

() Yes

() No



What is the per diem fee? \$ _____

12. Please describe your physical set-up, e.g., location, number of rooms and their function, specialized equipment/facilities. (If more space is required, continue on next page)

13. What are your admission criteria into the day program?

14. What are the objectives of your day program?

15. What services are provided to clients enrolled in the day program? (Please ☒ services provided)

- a. ☐ assessment
- b. ☐ health care, e.g., medication monitoring, health monitoring
- c. activity programming
 - ☐ recreational
 - ☐ activities of daily living
 - ☐ mobility (gross motor)
 - ☐ cognitive exercise, e.g., orientation, memory games
- d. ☐ behaviour management techniques
- e. ☐ supportive counselling
- f. ☐ referral to other community services
- g. ☐ other; please specify _____

Do you have any other comments about services provided to clients in the day program?

16. What services are provided to caregivers of clients enrolled in the day program? (Please ☒ services provided)

- a. ☐ respite
- b. ☐ health counselling re client's health
- c. ☐ teaching of behaviour management techniques
- d. education re:
 - ☐ Alzheimer's Disease
 - ☐ other available community resources
 - ☐ legal and financial matters
- e. ☐ counselling
- f. ☐ referral to other community services
- g. ☐ Family Support Groups
- h. ☐ other; please specify _____

Do you have any other comments about services provided to caregivers of clients in the day program?

17. Do you make home visits to clients enrolled in the day program and their caregivers?

() Yes

() No

18. Are individual plans constructed for clients and their caregivers?

() Yes

() No

Other Programs and Services

1. Do you offer home assistance to clients and their caregivers who are not enrolled in your day program?

() Yes

() No



Please indicate if service offered is primarily respite.

() Yes

() No

Please describe your home assistance program.

2. What services do you provide to the community?

a. () in-service presentations or workshops

b. () training of professionals re the management of the client with Alzheimer's Disease

c. () informing the community-at-large re Alzheimer's Disease

d. () student field placements

e. () other. Please describe (using the space provided on the following page if necessary)

3. What agencies/institutions/support services do you frequently use? Please indicate the type of service they provide.

Name of service

Type of service

Program Administration

1. Who administers the program? Please indicate if you are:
- a. () under the auspices of a hospital or other institution
 - b. () under the auspices of a volunteer society
 - c. () under the auspices of another organization; please specify _____
 - d. () the program is freestanding
 - e. () other; please specify _____
- _____

2. Please list staff positions, their professional qualifications (e.g., R.N., physiotherapist) and hours per week worked.

<u>Staff type</u>	<u>Professional qualification</u>	<u>Working hours per week</u>
-------------------	---------------------------------------	-----------------------------------

3. Do you use volunteers?

() Yes

() No



How many active volunteers do you have? _____

How many volunteer hours per week are typically contributed?
_____ hours

4. Please list your funding sources and the proportion each contributes to your budget. Please also indicate if these sources are private or public.

<u>Funding source</u>	<u>% budget</u>	<u>Private/public</u>
-----------------------	-----------------	-----------------------

5. Are you planning any changes to your program in the near future?
6. What have been your major problems in operating this program?
Have you resolved any of these problems?
7. Where do you feel your program has its greatest impact?
(you may check more than one)
- a. ☐ communities
 - b. ☐ clients
 - c. ☐ individual families
 - d. ☐ institutional facilities
 - e. ☐ advocacy

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8. Any other comments?

Thank you for your cooperation.

Programs Identified

1. The Family Respite Centre
2036 Westmoreland Street
Falls Church, Virginia 22043
2. The Casa Colina Hospital
Adult Day Centre
2820 North Garey Avenue
Pomona, California 91767
3. * The Riverside Adult Day Care Centre
220 South River Street
Plains, Pennsylvania
4. The House of Welcome Seniors Centre
Pat Taylor, Executive Director
Northshore Seniors Centre
620 Lincoln Avenue
Winnetka, Illinois 60093
5. * Dr. Dan Sands
Director
Harbour Area Day Care Centre
661 West Hamilton
Costa Mesa, California 92627
6. * Glanadale Day Centre
West Island Volunteer Bureau
164 Lakeshore Road
Pointe Claire, Quebec
H9S 4J7
PHONE: 697-0966
7. Mme. Helene Laprise
Alfred Desrochers Centre Accueil
5325 Victoria Avenue
Montreal, Quebec
H3W 2P2
PHONE: 731-3891

* Programs surveyed in this study.

8. * Mrs. Sonia Aronoff
Activity Plus
5700 Westbury Avenue
Montreal, Quebec
H3W 3E8
9. * Maimonides Hospital
Day Centre for Alzheimer's
Cote St. Luc
5795 Caldwell
Montreal, Quebec
H4W 1W3
PHONE: 483-2121
10. * Mr. John Panella
Burke Rehabilitation Centre
785 Mamaroneck Avenue
White Plains, New York
10605
11. * Gilda Jubas
Coordinator
Seneca Day Care for Seniors
1700 Finch Avenue East
Willowdale Ontario
M2J 4X8
PHONE: 492-9315
12. Barbara Keyes, R.N.
The Alzheimer's Disease
Day Treatment Program
Wisconsin Regional Geriatric Centre
2711 W. Wells Street
Milwaukee, Wisconsin
53208
13. * Mr. Joseph Maier
The Adult Day Centre
Fifteenth Street
Upland Avenue
Upland, Pennsylvania
19013
14. * Ms. Joyce Beckett
Program Coordinator
Richmond Heights Adult Day Centre
1802 Alexandra Avenue
Saskatoon, Saskatchewan
S7K 3C7

15. * Mr. Paul McCarty
Director
The Community Family Day
42 Water Street
Medford, Massachusetts
02155
16. Ms. Mary Jane Koloutek
Director
Milton Adult Day Care
1200 Brush Hill Rd.
Milton, Massachusetts
17. * Fiona Kennedy
The Day Program
Social Work Dept.
Parkwood Hospital
801 Commissioner's Road
London Ontario
18. * Mr. Paul McKinnon
Home Care Program
835 Weller Street
Peterborough, Ontario

Staffing of Programs Surveyed

Program	Staff Position	Professional Qualification	Hrs./Wk.
A	Program Director	-	40
	Nurse	RN	40
	Program Aide	BS	40
	Administrator	BS	40
	Nurses Aide	-	30
	Secretary	-	40
	Beautician	-	15
	Senior Aides (2)	-	20 (each)
	Custodian	-	15
B	Director	Psychologist	Full-time
	Asst. Director	BA (gerontology)	Full-time
	Program Assistants (2)	BA (gerontology)	Full-time
	Nurse	RN	1/4-time
	Program Assistant	-	Full-time
	Program Assistant	-	1/3-time
	Secretary	-	1/3-time
	Kitchen Assistant	-	1/3-time
C	Physician	MD	3
	Psychiatrist	MD	Consultative
	Coordinator	RN	Part-time
	Social Worker	MSW	Part-time
	Occupational Therapist	Registered	Part-time
	Recreologist (2)	BA-Recreation	Full-time (each)
	Special Care Counsellor	DEC	Full-time
	Special Care Counsellor	Tech. en Loisirs	Full-time
	Secretary	-	Full-time
D	Director	MA (social gerontology)	35
	Nurse	BS, RN, MA	35
	Art Therapist	MS	35
	Dance Therapist (2)	MS	14 (each)
	Recreation Therapist	BA	17.5
	Activity Therapy Aide	-	35
	Activity Assistant	BA	28
E	Director	MSW	4
	Service Coordinator	BA (psych.)	40
	Recreation Therapist	BA (recreational therapy)	40
	Day Care Workers (4)	-	20 (each)

Staffing of Programs Surveyed

Program	Staff Position	Professional Qualifications	Hrs./Wk.
F	Program coordinator	BSN	Full-time
	Psychiatric Nurse	RPN	Part-time
	Social Worker	BSW	1/2 -time
	Recreation/care Staff	-	Full-time
	Recreation/care Staff	-	Part-time
	Maintenance/Housekeeper	-	Part-time
	Dietary Aide	-	1/2 -time
G	Director/Nurse	BSN	40
	Activity Coordinator	CPN	40
	Social Worker	BSW	20
	Aides (4)	-	32.5 (each)
H	Animator	Special Care Counselor/ Social Work	Full-time
	Animator	BA (phys. ed.)	4/5 -time
	Intern	Certificate in Gerontology	Part-time
I	Volunteer run program: volunteers with backgrounds in nursing, social work and therapy.		
J	Social Worker	MSW	40
	Social Worker	MSW	10
	Recreation Specialist	Diploma in Recreation Leadership	12
K	Recreationist	-	7
L	Director	Social Work	40
	Activity Coordinators	RN	21

Persons Contacted During Tracking of Other Programs for Alzheimer's
Clients

Ms. Rachel Bellington	Alzheimer's Disease and Related Disorders Association, Inc. Chicago
Ms. Jean Bentley	Alzheimer's Society of Calgary
Ms. Thelma Cadieux	Société Alzheimer de Montreal
Ms. Sheila Casgrain	Community Psychogeriatric Service Cornwall, Ontario
Ms. Linda Ceci	Alzheimer Society, St. Catherines, Ontario
Mr. Jack Christie	Alzheimer Society London, Ontario
Dr. Arthur Dalton	Surrey Place Behavioural Centre Toronto, Ontario
Mr. J. Fisher	Alzheimer Society of Peel
Ms. Dorry Gould	Alzheimer Society National Office Toronto, Ontario
Mrs. Fran Hadley	Société Alzheimer Society of Ottawa-Hull Day Away/Home Assistance Programs

Mrs. Madeleine Honeyman	Société Alzheimer Society of Ottawa-Hull
Dr. Rob Hopkins	Alzheimer Society Kingston, Ontario
Ms. Fiona Kennedy	Social Work Dept. Parkwood Hospital London, Ontario
Ms. Mary Ann Outwater	Cambridge, Massachusetts
Ms. Betty Ransom	National Council on the Aging Washington, D.C.
Ms. Shirley Sharkey	Geriatric Day Hospital, Toronto, Ontario
Ms. Cal Shell	Alzheimer's Society Winnipeg, Manitoba
Dr. Mary Tierney	Sunnybrook Medical Centre
Mr. J. van den Hooven	Alzheimer Society Vancouver, British Columbia
Institute for Elderly People	Montreal, Quebec